

ANGLIA RUSKIN UNIVERSITY

Faculty of Health, Education, Medicine and Social Care

A PLURALISTIC APPROACH TO PEER SUPPORT

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ANGLIA RUSKIN UNIVERSITY

ABSTRACT

FACULTY OF HEALTH, EDUCATION, MEDICINE AND SOCIAL CARE

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Eleanor Townsend

Research Purpose: This research explores how individuals with experience of emotional or mental distress use different forms of community-based peer support to enhance their well-being, specifically in one to one, group and online settings.

Research Background: Attention has been paid, in recent years, to the potential of peer support to enhance the well-being of individuals experiencing mental or emotional distress. However, existing studies tend to concentrate on forms of peer support in isolation. Recent research suggests that a plurality of use exists, whereby individuals actively choose to access more than one form of peer support to improve their well-being. It is important to revisit the landscape of peer support to develop a better understanding of the motivations and experience driving this plurality of use.

Research Design: Data was collected through 18 in-depth qualitative semi-structured interviews. Participants were recruited through a strategy of purposive sampling. All had experience of at least two forms of peer support.

Research Findings: Individuals use different forms of peer support in both sequence and combination to enhance their well-being. Personal agency plays an important role in how and why individuals use different forms of peer support. Different forms of peer support make nuanced, diverse and sometimes unique, contributions to individual well-being, especially in supporting individuals to reframe their experiences, source new forms of social support and participate in reciprocal giving.

Research Conclusions: Research findings demonstrate the importance of community-based peer support as part of the welfare landscape and illuminate new complexities around the way in which individuals use and experience different forms of peer support. Whilst mental health policy tends towards short-term use and formal one to one peer support, this research illustrates that individuals benefit from using a variety of forms, and the importance of ensuring the availability of different forms of peer support.

Keywords: community-based, peer support, mental health, well-being, pluralistic

Table of Contents

1. <u>Chapter One: Introduction</u>	1
1.1 How I came to this study	1
1.2 Structure of this thesis	3
1.3 A note on language	5
2. <u>Chapter Two: Peer Support in the UK</u>	7
2.1 Introduction	7
2.2 Approaching the literature	7
2.2.1 <i>Critically appraising the literature</i>	10
2.2.2 <i>Focusing on community-based peer support</i>	11
2.3 Terminology around peer support	14
2.4 Defining peer support	17
2.5 Important features of community-based peer support	18
2.5.1 <i>Shared experience and experiential knowledge</i>	21
2.5.2 <i>Recovery</i>	23
2.5.3 <i>Reciprocity</i>	25
2.5.4 <i>Ownership and power</i>	26
2.6 A complex and evolving landscape	28
2.6.1 <i>The service user movement and birth of the 'single issue group'</i>	29
2.6.2 <i>Technological Developments</i>	31
2.6.3 <i>Individualisation and peer support in recent UK mental health policy</i>	34
2.7 International perspectives	37
2.8 Chapter Summary	38
3. <u>Chapter Three: Engagement with peer support and outcomes</u>	40
3.1 Introduction	40
3.2 Why individuals use peer support	41
3.2.1 <i>Motivations</i>	41
3.2.2 <i>Accessibility</i>	45
3.2.3 <i>Referrals and signposting</i>	47
3.3 Patterns of participation and engagement	48
3.3.1 <i>Frequency and length of engagement</i>	48
3.3.2 <i>Active and passive participation</i>	50
3.3.3 <i>Withdrawing from peer support</i>	51
3.4 Frameworks of understanding	52
3.4.1 <i>Treatment evaluation approaches and randomised control trials as the 'gold standard'</i>	53
3.4.2 <i>Well-being approaches</i>	53
3.5 Processes and outcomes from engaging with different forms of peer support	55
3.5.1 <i>Symptom Reduction Studies</i>	56
3.5.2 <i>Well-being Studies</i>	59
3.6 Rationale for this study	67
3.7 Chapter Summary	70

4. <u>Chapter Four: Methodology</u>	71
4.1 Introduction	71
4.2 Paradigm of inquiry	71
4.2.1 Interpretivism	73
4.2.2 Ontology	74
4.2.3 Epistemology	75
4.2.4 Research strategy	76
4.2.5 Limitations of interpretivism	77
4.3 Qualitative Methodology	78
4.3.1 Qualitative Interviewing	79
4.3.2 Critiques of qualitative methodologies	81
4.4 Research design	82
4.4.1 Recruitment of research participants	82
4.4.2 Development of an interview guide	86
4.4.3 Data analysis	88
4.4.4 Coding the data	89
4.5 Quality of research findings	90
4.5.1 Credibility	90
4.5.2 Transferability	91
4.5.3 Dependability and confirmability	92
4.6 Reflexivity and power in qualitative research	93
4.7 Ethics	95
4.8 Limitations of the research	97
4.9 Chapter summary	97
5. <u>Chapter Five: Findings</u>	98
5.1 Introduction	98
5.2 Descriptive Background	98
5.3 How and why individuals use different forms of peer support	102
5.3.1 Motivations for using peer support	102
5.3.2 First encounters with different forms of peer support	108
5.3.3 Patterns of participation	114
5.3.4 Barriers to accessing different forms of peer support	124
5.3.5 How peer support is used alongside professional support	129
5.4 Conceptualising Peer Support	135
5.4.1 Complexity of the peer support landscape	135
5.4.2 Shared experiences	137
5.4.3 Peer and non-peer friendships	141
5.4.4 Terminological complexities	142
5.5 Contribution of different forms of peer support to individual well-being	144
5.5.1 Reframing and self-acceptance	144
5.5.2 Development of new forms of social support	151
5.5.3 Reciprocal giving and increased self-esteem	157
5.5.4 Developing coping strategies and maintaining day to day well-being	161
5.6 How different forms of peer support challenge individual well-being	171
5.6.1 Experiences of conflict, misunderstandings and distress	171
5.6.2 Maintaining well-being whilst supporting others	176

5.6.3 <i>Funding problems, group closures and disruption</i>	179
5.7 Chapter Summary	181
6. <u>Chapter Six: Discussion</u>	183
6.1 Introduction	183
6.2 How we define and conceptualise peer support	184
6.2.1 <i>Key ingredients/ features of peer support</i>	186
6.3 How personal agency influences why and how people use different forms of peer support	188
6.3.1 <i>Deciding to use peer support</i>	188
6.3.2 <i>Personal agency and ongoing use of different forms of peer support</i>	190
6.4 How individuals with experience of mental or emotional distress use different forms of peer support to enhance their well-being	193
6.4.1 <i>Social support</i>	193
6.4.2 <i>Reciprocity/ self-esteem</i>	195
6.4.3 <i>Reframing experiences of mental or emotional distress</i>	198
6.5 How engaging with peer support can challenge the recovery journey	199
6.5.1 <i>Experiences of conflict and distress</i>	199
6.5.2 <i>The potential emotional toll of different forms of peer support</i>	201
6.6 Implications for understanding the peer support landscape, policy and practice	202
6.7 Chapter Summary	205
7. <u>Chapter Seven: Conclusion</u>	206
7.1 Introduction	206
7.2 Original research contributions	206
7.2.1 <i>Conceptual/ theoretical contributions</i>	209
7.2.2 <i>Methodological contribution</i>	212
7.3 Limitations of this study and challenges posed by community-based research	215
7.4 Areas for future research	217
7.5 My reflexive journey	218
References	219
 List of Appendices	
Appendix One: Participant Recruitment.	236
Appendix Two: Interview Guide	237
Appendix Three: Ethical approval paperwork	239
Appendix Four: Participant Information Sheet and Consent Form	244

List of Tables

	Page
Table One: Search strategy inclusion and exclusion criteria	9
Table Two: Search terms	10
Table Three: Features of peer support	20
Table Four: Age breakdown of interview participants	99
Table Five: Forms of peer support used by each interview participant	101

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Chapter One

Introduction

1.1 How I came to this study

Working in the voluntary and community sector in London over the last few years, it has been hard to escape the term 'peer support'. Both government and funders have sought out new peer related initiatives and a plethora of activities have emerged, with peer support being increasingly seen as a solution to numerous individual and community-based challenges. Working for an organisation that had designed a time currency explicitly to encourage exchanges of time, skill, support and experience between people, I saw first-hand the potential of peer support to enhance well-being, and how such initiatives could re-build the connections that had once existed between people but which had become eroded as people lived faster and struggled to connect.

However, as I attended different peer support groups and organisations, I started to wonder more about what made some so effective and others less impactful. Whilst big national charities were increasingly interested in how peer support groups could support their beneficiaries, they also struggled to make new groups independent and to find 'a sustainable peer support model'. I also started to question what peer support really was; it seemed both to be everywhere, the foundation of support for people in all stages of their lives, but also so distinct to the support we might seek out from medical professionals or from traditional support structures in our family and friends.

Peer support is not new, but it is receiving unprecedented attention, especially in the area of mental health, which nationally is posing us a larger challenge than ever before. When I saw the Vice Chancellor Studentship advertised by Anglia Ruskin University, I saw an opportunity to really take some time to reflect and explore some of these questions in more detail. Once immersing myself in the literature, I started to understand the huge complexity of the peer support landscape in the UK and the considerably different ways in which it has been approached by academics and researchers.

The idea for a study that introduced a pluralistic approach to peer support first emerged following indications from a national lottery funded study entitled 'ESTEEM' (Effective Support for Self Help/Mutual aid groups). This found that individuals use different forms of peer support concurrently and formed the basis of a Vice Chancellor Studentship which I was awarded in 2017. Whilst the focus of the 2013 ESTEEM study was how practitioners could best engage with, and support self-help groups, interviews and focus groups with 21 self-help groups also revealed the ways in which some groups were employing online technologies to extend their engagement with members (Boyce et al 2014). This example of dual use of peer support created new research questions around how far this plurality extended, and how individuals were using different forms of peer support to enhance their well-being.

In the last twenty years, there has been an increase in the complexity of the peer support landscape in the UK. The 2013 report 'Piecing Together the Jigsaw' commissioned by the national charity Mind, and authored by Faulkner et al, was an important step toward understanding this complexity. A subsequent evaluation of the national Side by Side Peer Support Programme in 2017 started to consider different forms of peer support together and how potential mechanisms for well-being, such as reciprocal giving, were experienced in these different peer support environments (Billsborough et al 2017). My study has sought to take these findings a step further by exploring individual peer support journeys in depth and how, in combination or sequence, individuals have engaged across the 'jigsaw', and to what end.

Although the field work for this study was completed in the early days of the COVID-19 pandemic, there is no doubt that the social changes brought about by repeated national lockdowns and the need for social distancing have brought even more salience to a study that examines the different ways in which individuals access support. Many face to face peer support groups have been forced online and this has created new opportunities for discussion around what is lost when face to face interaction is not possible, as well as the potential for online relationships to offer vital support in extremely difficult times. This is a theme I revisit in my conclusion, when considering future areas for research.

1.2 Structure of this thesis

This thesis is structured as follows:

Two initial chapters explore the existing literature around peer support in the UK and provide context to the research conducted for this thesis. In Chapter Two, I examine nuances around the terminology used to explore peer support and definitional challenges. The chapter reflects on three key trends; the birth of the single issue group, technological developments and individualisation, alongside the introduction of formal peer support to mental health services. Consideration is given to how each of these trends has influenced the development of formal and informal forms of peer support in the UK. Chapter Two concludes with a brief international perspective and examples of how the evolution of peer support in the UK compares to that of other nations. In Chapter Three, I start to consider the existing literature on why people choose to engage with peer support, before looking at what is already known about how different forms of peer support contribute to individual well-being. I reflect on two frameworks through which it is possible to assess the impact of peer support; treatment evaluation and well-being perspectives, and the key differences between these. Finally, I identify the existing gap in knowledge and the subsequent rationale for this study. I call specifically for the need for a pluralistic approach to look across different forms of peer support (one to one, face to face, online), to consider how they are used in sequence or combination, and to better understand the unique contribution of each form to individual well-being.

In my methodological chapter (Chapter Four), I introduce the central research question for the study: How do people who have experienced mental or emotional distress use different forms of community-based peer support to enhance their well-being?'

And how within this, the research seeks to explore:

- Motivations of individuals for accessing different forms of peer support
- Pathways between different forms of peer support
- Types of participation and patterns of use
- Barriers to accessing different forms of peer support

- Individual perceptions of how different forms of peer support enable participants to enhance their well-being

In this chapter, I situate the research in an interpretivist research paradigm and provide a rationale for the use of an abductive research strategy and qualitative methodology to explore how people use online, one to one or group peer support in combination to enhance their well-being. I then outline the specificities of the research design, including the approach taken to sampling, data collection and data analysis. I conclude with a consideration of the strategies employed to ensure trustworthiness of findings and my positionality as a researcher.

I present the findings from my data collection in Chapter Five. The chapter is divided into five sections. Firstly, a brief description is given of the individuals who comprised the interview sample to provide context to the findings. The second section explores why and how people use different forms of peer support. The third section discusses how different ideas of ‘peer’ were presented by participants. The fourth section presents the key themes that emerged around how different forms of peer support were considered to support participant well-being. In the final section, I outline key findings around the potential ways different forms of peer support can pose a challenge to individual well-being.

In Chapter Six I discuss how my findings increase our understanding of how individuals use different forms of peer support and the value of taking a pluralistic approach to study the complex relationship between different forms of peer support and well-being. This is presented in five thematic areas. Firstly, I consider the implications of this study for how we define and conceptualise peer support. Secondly, I discuss how personal agency influences why and how individuals use different forms of peer support. Thirdly, I consider the contribution of this study to new understandings of how different forms of peer support are used by individuals to enhance their well-being and fourthly, how engaging in different forms of peer support can potentially hinder individual recovery. Finally, I reflect on the overall implications for our understanding of the wider peer support landscape as well as for policy and practice.

This thesis concludes with a description of how this study provides a unique contribution to knowledge. I argue that my findings have enabled a far more nuanced understanding of how different forms of peer support enhance well-being, especially in three areas: reframing experiences, finding sources of social support and the nature of reciprocal relationships. I also contend that this study has presented a new perspective by illustrating the complex ways in which individuals use different forms of peer support in combination and sequence. In the following section, I examine the limitations of the study and the challenges posed by conducting research on peer support in community-based settings, before identifying areas for future research. The latter responds to the limitations of my study, and seeks to build on my findings, and take into account the societal changes that have taken place as a result of the COVID-19 pandemic. The study ends with a brief reflection on my personal journey throughout my three years of the PhD and some of the surprising challenges I have faced along the way.

1.3 A note on language

This study is situated in an epistemology of constructivism rather than social constructionism. However, whilst considering how to frame my research question, I was influenced by academics such as Walker (2006), who examine ideas of mental illness through a social constructionist lens to argue that the language used around mental health not only describes a reality but can serve to create a reality. This can have powerful implications for both individuals and society; a subject addressed by Dr Antonis Kousoulis, a Director at the Mental Health Foundation, in 2019:

‘In the way that we have framed our societies, people living with a long-term mental health problem can struggle to recover their personal identity (as a parent, spouse, co-worker, volunteer, student etc.). Therefore, how we talk about this experience of mental illness could play a positive and influential role in the recovery process for millions of our fellow citizens. Identifying someone as simply a “patient”, “service user” or a “schizophrenic” implies that this is all the person is - that this diagnosis defines them. Instead, describing someone as experiencing mental illness can help to allow for other parts of their identity to still exist. We often use the word “suffer” when it comes to mental ill health. Whilst it is accurate that we should

acknowledge the actual impact and suffering that people experience, we also need to be careful not to imply that a diagnosis equates to a “life sentence” of suffering. We now know that following a diagnosis, we can engage in positive recovery pathways, thrive in our workplaces and be dependable family members. So, if we instead use expressions like “people who use mental health services”, “people who experience mental health problems”, “people living with depression” we could achieve a more holistic and accurate view of the experience of ill-health’. (Mental Health Foundation, 2021).

In my research I wished to avoid terms such as ‘mental health problems’ and ‘mental illness’ which pre-define experiences and introduce specific negative connotations. I decided to talk of ‘individuals with experiences of mental or emotional distress’, to put the identity of the person first (rather than their experience), and to avoid the suggestion that such experiences define an individual across their life course. Finally, I wanted to ensure this study was open to participants who do not have or accept a clinical definition of their experiences or subscribe to a bio-medical model of mental health.

This note on language illustrates just one of many complexities I have encountered in this study when it comes to the terminology and words used to describe experiences of mental and emotional distress, peer support and well-being. This has proved challenging in many aspects; not least in the initial review of the literature. However, these complexities demonstrate the potential value of a pluralistic approach to peer support; as an approach which seeks to embrace the often messy reality of life.

Chapter Two

Peer Support in the UK

2.1 Introduction

I start this chapter by explaining my approach to the existing literature on peer support in the UK. I then discuss the different terminology used, both in research and practice around peer support, as well as different definitions and perspectives on the key features of community-based peer support. In the second half of the chapter, I explore how three key trends (social movements and the rise of the single-issue group, technological developments and individualisation and recent UK mental health policy) have led to the development of a complex peer support landscape in the UK. Finally, I offer some international perspectives on peer support to further demonstrate the importance of national socio-political circumstances in shaping how peer support is understood and supported in different countries.

2.2 Approaching the literature

Arshed and Danson (2015) identify the four main types of literature review as: traditional or narrative, systematic, meta-analysis and meta-synthesis. For the purposes of this study, I judged a traditional or narrative literature review to be most appropriate as it would allow me to review a large body of literature and to fully understand current theories, trends and themes, as well as the current gap in the understanding around pluralistic experiences of peer support. Arshed and Danson (2015: 37-38) describe the purpose of this type of review as being:

‘to analyse and summarise a body of literature. This is achieved by presenting a comprehensive background of the literature within the interested topic highlight new research streams, identify gaps or recognise inconsistencies. This type of literature review can help in refining, focussing and shaping research questions as well as in developing theoretical and conceptual frameworks’.

I adopted the following questions, proposed by Arshed and Danson (2015:40), as a framework for my literature review:

- What do you know about the research area?
- What are the relationships between key ideas, dynamics and variables?
What are the current theories, trends and themes?
- What are the inconsistencies, implications and shortcomings of previous studies?
- What needs further investigation because evidence is lacking, inconclusive, contradictory and/or limited?
- What methodological approaches have been taken and why? Are the methodological approaches justified?
- Why does this area of research need to be studied further?
- What contribution will your work make to the current debate?

Through my literature review, I sought to understand what efforts had already been taken to understand pluralistic experiences of peer support. As such a topic could encompass numerous different forms of peer support, initially I took a broad but systematic approach to the existing literature on peer support. This involved firstly reviewing all of the databases and subject areas on the Anglia Ruskin Library Website and determining that the most relevant subject areas were: Medical Sciences, Nursing, Public Health, Social Work and Social Policy. I then consulted a subject specialist librarian and my supervisors on the most appropriate databases to focus on within these subject areas. The databases chosen were: CINAHL Plus, Social Care Online, Web of Science, JSTOR, PubMed, AMED, Social Policy and Practice (OVID), the Social Science Database, PsycINFO, and the Cochrane Library. I also reviewed a number of sources of grey literature, including national and international government websites and publications produced by large UK national charities.

The literature on peer support covers numerous different conditions. As such, a pluralistic approach could focus on the experiences of individuals living with a number of conditions such as cancer, stroke survivors, or long term health conditions such as diabetes or chronic fatigue. It could also focus on individuals at a particular life stage or life experience, such as university students or new parents. As it would not be feasible to cover all such literature in sufficient depth, for this thesis, I took the decision to focus primarily on individuals engaging in peer support because of experiences of mental or emotional distress. This was because peer

support is well-established in this area, and I believed, was more likely to facilitate a study which sought to look in detail across different forms of peer support. However, it is important to note that in some instances, literature has been included which covers other conditions and life experiences. This is because the self-help literature, especially on face to face groups, often brings together a number of groups which focus on different conditions or life experiences, one example of this being the 2013 ESTEEM study. In order to provide clarity, I have specified when the literature being discussed covers conditions or life circumstance beyond experiences of mental or emotional distress.

In addition to a focus on experiences of mental and emotional distress, I also developed a number of further inclusion and exclusion criteria to focus my searches on the areas I felt to be of most importance.

Table One: Search strategy inclusion and exclusion criteria

Inclusion	Exclusion
<p>Local, National and International published academic literature – primary and secondary sources.</p> <p>Books and book chapters.</p> <p>Policies and guidance documents.</p> <p>Grey literature e.g. charity reports.</p> <p>Peer reviewed articles.</p> <p>Written in English.</p> <p>Quantitative and Qualitative.</p> <p>UK, EU and International - apart from policy literature which will involve inclusion of UK policy only.</p> <p>All mental health conditions.</p>	<p>Non-English language papers.</p> <p>Full text not available through interlibrary loans.</p> <p>Literature on children and adolescent mental health.</p> <p>Literature that focuses on the peer support worker role in clinical settings/ recommendations for successful integration of peer support within clinical services (e.g. job descriptions).</p> <p>Literature on peer support accessed by caregivers/ family of people with mental health problems.</p> <p>Individualised self –help.</p> <p>Effectiveness studies of one to one intentional peer support in clinical settings.</p>

I quickly became aware of the varied terminology being used in the literature to describe terms such as peer support and mental health. In response I diversified my search terms to include a number of synonyms, to ensure robust coverage of the literature.

Table Two: Search terms

Concept	Synonyms
Peer support	Mutual aid, self-help, support group, user led (secondary aim rather than primary), peer supporters, mutual support, peer provided services, mutual help, service user group.
Mental health	Mental illness, mental wellbeing, mental health problems, depression, anxiety, recovery, well-being
Online support	Online forums, digital, internet support
Face to face	Self-help groups, peer support groups, mutual aid groups, service user groups, support group
One to one support	Befriending, peer support workers, peer support volunteers, peer brokers, peer mentors
Motivations	Aspirations, hopes, opportunities
Barriers	Challenges, exclusion, excluded, access

To ensure relevance, I focused on literature from the last twenty years. However, some older contextual and theoretical literature was included, for example on research philosophies or important theoretical contributions, such as Borkman's theory of experiential knowledge.

2.2.1 Critically appraising the literature

Applying the search strategy detailed above generated a large number of articles. I reviewed the abstracts of all articles and excluded anything which did not fit my inclusion criteria. Having refined the body of literature under review, I turned my attention to critically appraising the remaining full journal articles. For this, I used the Qualitative Critical Appraisal Skills Programme Checklist (Critical Appraisal Skills Programme, 2021). I adapted the checklist as I was reviewing both qualitative and quantitative literature to the following questions:

- Is there a clear statement of the aims of the research?
- Is the methodology appropriate?
- Was the research design appropriate to address the aims of the research?
- Was the recruitment strategy appropriate to the aims of the research?
- Was the data collected in a way that addressed the research issue?
- Has the relationship between researcher and participants been adequately considered? (if appropriate)
- Have ethical issues been taken into consideration?
- Was the data analysis sufficiently rigorous?
- Is there a clear statement of findings?
- How valuable is the research?

This strategy enabled me to develop the initial outline of my literature chapters. For Chapter Two, I focused on contextual literature on peer support, such as the way in which peer support has been defined and conceptualised. For Chapter 3, I focused on literature which explored in more depth how individuals engage with different forms of community-based peer support (online, face to face group and one to one). From this point, I then took a 'snow-balling approach', using the references from each article as a starting point for further reading.

Initial searches took place from January – July 2018. A second round of searches took place from August – December 2020 to ensure that the review was up to date.

2.2.2 Focusing on community-based peer support

The review of the literature drew my attention to the many complexities of peer support in the UK today and how quite different forms of peer support were considered under one wide umbrella. I found Bradstreet's (2006) categorisation of peer support into three activities: informal peer support, peer support that takes place within peer run groups/ programmes and formal peer support within mental health services, very helpful. Having considered the key characteristics around these three potential forms of peer support, I decided to focus on 'community-based' peer support. This is peer support that takes place outside of a medical service setting and can be informal or organised by peers. It does not include formal peer

support where roles are created in clinical services for individuals with lived experience of mental distress (Bradstreet 2006). Such peer support is also sometimes described as 'intentional' because it facilitates:

'relationships that are entered into intentionally—as opposed to occurring naturally—and that evolve in clinical or other formal service settings— as opposed to taking place in the broader community' (Davidson et al 2006:445).

This decision was taken for a number of reasons, firstly, there have been both numerous recent studies and systematic reviews which have examined this form of peer support in depth (see White et al 2020, Mahlke et al 2017, Johnson et al 2018, Wroblewski et al 2015, Walker and Bryant 2013, Simpson et al 2014). It was also questionable whether I might be able to obtain the relevant NHS ethical approval to conduct research in mental health settings whilst keeping to the three-year funded period of my studentship.

However, perhaps more significant were the key differences between peer support that takes place in a service setting as opposed to a community setting. Describing formal or intentional peer support in the US health system, Davidson et al (2006) stresses the asymmetrical nature of such peer support relationships and how this differs to other forms of peer support:

'In both mutual support groups and consumer-run programs, the relationships peers have with each other are thought to be reciprocal in nature; even though some peers may be viewed as more skilled or experienced than others, all participants are expected to benefit. We conceptualize peer support, in contrast, as involving 1 or more persons who have a history of mental illness and who have experienced significant improvements in their psychiatric condition offering services and/or supports to other people with serious mental illness who are considered to be not as far along in their own recovery process. Unlike mutual support and consumer-run programs, peer support is thus defined as involving an asymmetrical—if not one-directional—relationship, with at least 1 designated

service/support provider and 1 designated service/support recipient.’
(Davidson et al 2006:444).

The largely unidirectional nature of formal peer support relationships has led to concerns that the introduction of peer support workers into mental health services is professionalising the relationship that is at the heart of the helping process (explored in Faulkner and Kalathil 2012). The formalised peer support introduced into psychiatric systems often offers participants minimal ownership, with access to a limited number of structured one to one sessions, offered as part of their ‘treatment’. Gillard (2019:343) questions whether such time restrictions are an ‘anathema to peer support as it naturally occurs in the real world’ and Watson (2019b:26) identifies how some have seen this development of peer support as a misuse of survivor knowledge with ‘controlling practices’ left intact. Such concerns have led scholars to question whether it is possible to effectively ‘transplant’ peer support into mental health services, or if by doing so, we are in fact creating something quite different to traditional ideas of peer support:

‘As the focus on empowerment-type outcomes suggests, this is peer support that aims to strengthen the individual, to enable the individual to cope better with their mental health. Important of course, but reflecting an essentially medical model of mental health; that there is something wrong with you that a peer worker can support you to fix.’ (Gillard 2019:341)

Trained peer support workers, as paid employees or as volunteers, are also an aspect of the community peer support landscape. Here too, issues of asymmetric helping relationships could also be a consideration. However, outside of the service setting, such intentional one to one peer support relationships are not presented as strongly as part of a medicalised treatment. The literature on community-based one to one peer support is less comprehensive, and relatively little is known about how individuals experiencing mental or emotional distress might use this form of peer support alongside face to face peer support groups, online or informal one to one peer support in a community-based setting. As such, I chose to include literature which looked at formal one to one peer support in a community-based setting.

In this thesis, I wanted to understand the potential intentionality around why individuals chose to engage with different forms of peer support and the natural patterns of engagement that emerge when individuals are able to choose for themselves when and how they engage with different forms of peer support. As such, community-based peer support, or peer support outside of service settings offered the most 'natural' research environment in which I could try to understand those choices and the impact of different forms of peer support on well-being.

This introduction has already touched on some of the complications that exist around the terminology used to describe peer support. This is explored in the following sections, alongside different definitions of peer support and important features of community-based peer support. I then turn my attention to the complex peer support landscape in the UK, which I argue has been shaped by three key trends: the service user movement and the development of the single issue group from the 1970s, technological developments, and UK health policy since the late 1990s, which has increasingly focused on personalised approaches to health and recovery. Finally, I present some international perspectives which further demonstrate the importance of national socio-political context in shaping national landscapes of peer support.

2.3 Terminology around peer support

What we might now call peer support has been, and still continues to be, referred to in the literature using a range of terms. Borkman (1999) reflects on the struggles that researchers have experienced with terms such as self-help, mutual aid and support groups, all of which can be argued to be related and express similar ideas and how this has been further complicated by the use of varied definitions for identical terms. This confusion extends beyond the academic literature into practice, and is illustrated by an observation from Faulkner et al (2013:7) on the way in which terms such as peer support, self-help and mutual support are 'used interchangeably' in the UK. Service users or participants in peer support themselves also employ a number of different terms, considering themselves for example as community, support or friendship groups (ESTEEM Project Final Report 2013:4).

Much of the discussion around terminology has developed from the literature on face to face peer support groups, where the different terms used to describe peer support are recognised to bring different nuances. Seeböhm, Munn-Giddings and Brewer (2010:25) examine the language around self-help groups, peer support groups and service user groups, noting that the choices taken with regards to the use of different terms used by groups may be as much to do with 'motivation, perception and culture' as it is do with distinctive features of the groups themselves. Peer support activities do not take place in isolation; in their 2003 survey of mental health support groups Wallcraft, Read and Sweeney found that peer support groups identified as delivering numerous different types of activities (Wallcraft, Read and Sweeney 2003). This illustrates the multi-faceted nature of groups where peer support can take place. A more recent Mind report also found that groups delivering support often choose to place emphasis on one of several areas of activity (Faulkner et al 2013).

Borkman (1999:4) explores the meaning of several terms, and defines mutual aid as a term that refers to 'individuals joining together to assist one another either emotionally, socially or materially'. Whilst this recognises the reciprocal relationships held by individuals in a mutual aid transaction, it does not make direct reference to the nature of individuals involved in that transaction and whether they are able to offer that support because they bring the same experiential knowledge to the table. Mutual aid can take the form of an economic cooperative for example and can arguably be provided by individuals regardless of whether both individuals have the same lived experience.

Mutual aid is often used in conjunction with the term self-help. This is a term which can refer to the employment of individual self-help resources, such as self-help books. In their examination of self-help versus mutual aid terminology, Humphreys and Rappaport (1994) propose that the use of self-help alone suggests an individualism that does not express the communal nature of groups. However, in a wider sense, self-help can be defined as 'an individual's taking action to help him or herself, often drawing on latent internal resources and healing powers within the context of his or her lived experience with an issue or predicament' (Borkman 1999:4). Borkman contends that joining these two terms together 'produces a special form of interdependence in which the individual accepts self- responsibility

within a mutual aid context – individuals maintaining independence while helping others and receiving help from others' (1999:5).

Further terms found in the literature include service-user groups and support groups. The term service-user itself has developed 'as a generic term to describe people who receive, have received or are eligible for health and social care services, particularly on a longer-term basis' (Beresford 2005:471). Seebohm, Munn-Giddings and Brewer (2010:25) suggest that undertaking positive action to improve services and secure rights for service users is a high priority for groups that choose to label themselves as service user groups, alongside peer support activities. Such groups potentially can be seen to be more outward looking than a mutual aid or self-help group, with a greater emphasis on the change they wish to see in the outside world rather than for themselves internally (Seebohm, Munn-Giddings and Brewer 2010).

Loat (2011) argues that it is necessary to look to the role of professionals in facilitating peer support activities in order to distinguish between a support group and a mutual aid support group (the latter of which would be facilitated by group members rather than a mental health professional). However, Munn-Giddings and McVicar (2007:27) stress the need to remember that the 'semantic distinctions' employed by academics may not always play out in the same way in practice, as 'many groups run for and by their members refer to themselves as support groups'. A helpful distinction perhaps is that drawn by Borkman (1999) who argues that it is when professional knowledge overpowers the experiential knowledge of participants, that they cannot be perceived to incorporate a self-help approach.

Whilst the discussion above has developed in relation to face to face peer support groups, it is of interest that a variety of terms are also used to describe online peer support; with the use of 'online support group' one of the most popular terms. 'Self-help online' or 'Internet Self-help' are also used to describe online peer support, capturing the independent action being taken by the individual to help themselves, referenced by Borkman above. However, this is not used alongside the term 'mutual aid', suggesting perhaps less emphasis on collective support in an online environment. Although the focus of this study is not on intentional one to one peer support relationships in a medical setting, it is of interest to note that this is where

the term 'peer support' is used the most and the terms 'self-help' or 'mutual aid' are absent. The different uses of terminology for different forms of peer support hint at the distinct traditions and philosophies informing each form and raise an interesting question around the impact for individuals seeking to use different forms of peer support to enhance their well-being.

In this study, I have chosen to employ the term 'peer support' in order to place emphasis on forms of support than can be offered to individuals by others who have experienced a similar problem or life experience. Recognition of the unique support that can be offered by others with direct lived experience of mental or emotional distress can be dated back as far as 1793 (Davidson et al 2012). However, in recent years, peer support as a term has taken on new meaning as 'something of a juggernaut within contemporary mental health policy and practice' (Davidson et al 2012:123). In the UK, this is evident with mentions of peer support becoming increasingly common in national policy (for example, the Department of Health's No Health with Mental Health Implementation Framework published in 2012 and the findings of the Five-Year Forward View for Mental Health Taskforce published in 2016). Its wide usage within the mental health field within policy and practice makes it an appropriate focus of study. However, despite the increasing frequency of use of the term peer support, no universal definition of what this means currently exists (Repper and Carter 2010). Therefore, consideration must be given to what can be understood by the term 'peer support'.

2.4 Defining peer support

Most simply, peer support can be considered to be 'a situation where people with experience of mental health problems are offering each other support based on their lived experience' (Faulkner et al 2013:6).

A number of papers and reports have chosen to use the definition put forward by Shery Mead, a campaigner and advocate for peer support within mental health services in the United States. Mead draws a key distinction between peer support and professional services, defining peer support as:

'A system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain.' (Mead 2003:6).

Repper and Carter (2011: 395-396) refer to Mead's 2003 definition but also stress the important distinction that should be drawn between peer run services and formal one to one peer support relationships. They suggest that the definition offered by Solomon (2004:393) as a way to capture the mutuality of peer support relationships:

'social emotional support, frequently coupled with instrumental support, that is mutually offered or provided by persons having a mental health condition to others sharing a similar mental health condition to bring about a desired social or personal change'

For me, this is the definition which most fully captures the essence of peer support and which will be used for the purposes of this study. This is because it recognises the different forms of support that can be offered, the importance of mutual exchange of support so that participants are given the opportunity to both give and receive support, and the underlying aspiration of those participating to create change in their lives.

2.5 Important features of community-based peer support

As new forms of peer support have emerged, numerous reports and articles have considered the key features of peer support. Also described as principles, values or critical ingredients, such criteria seek to identify what is and what isn't peer support and the standards to which peer support activity should be upheld. The table below summarises a number of efforts to capture such features. This selection demonstrates the important contribution of reports commissioned by Mental Health Charities to progressing thinking around standards of peer support (e.g. Piecing Together the Jigsaw (Faulkner et al 2013), an evaluation of the Side by Side peer support programme (Billsborough et al 2017), The Freedom to be, The Chance to

Dream (Faulkner, and Kalathil 2012)). However, it also serves to illustrate how such frameworks are often developed with intentional or formal one to one peer support in mind, most explicitly demonstrated by the consultation on a Peer Support Worker Competency Framework for Mental Health (Royal College of Psychiatrists/ University College London, 2020). Some such frameworks have been prompted by concerns around professionalism of peer support and the loss of key values as peer support is incorporated into mental health services (explored in Faulkner and Kalathil 2012).

Table Three: Features of peer support

Solomon (2004)	Critical ingredients of peer provided services: Use of experiential learning process Use of mutual benefit Use of natural social support Voluntary nature of the service Primary control of service by individuals with psychiatric disorders
Lived Experience Leading the Way (Basset et al 2010)	12 Principles of peer support: Mutuality Solidarity Synergy Sharing with safety and trust Companionship Hopefulness Focus on strengths and potential Equality and empowerment Being yourself Independence Reduction of stigma Respect and inclusiveness
Freedom to be, the chance to dream (Faulkner, and Kalathil 2012).	Key values: Respect Shared responsivity Empathy A non-judgemental attitude Equality Confidentiality Trust Openness Willingness to be supportive and helpful and also to receive support (mutuality).
Mental health peer support in England: Piecing together the jigsaw (Faulkner et al 2013).	Principles generally endorsed by peer support projects: Mutuality, respect, a non-judgmental approach, inclusivity, equality Peer-led Social inclusion, shared learning, wellbeing Sense of agency or power 'to be aimed for' Reciprocity not always considered to be possible A commitment to equality and diversity. (p28)
Scottish Recovery Network Values Framework (2013 reprint)	Values Framework: Hope Experience Authenticity Mutuality Empowerment Responsibility

Evaluating the Side by Side peer support programme (Billsborough et al 2017)	Core Values: Freedom to be oneself Two-way interactions Human connections Commonality of experience Social and emotional distress Safety Choice and control
Self Help UK 2020 (Self Help UK, 2020)	The philosophy of self-help is based on three elements: <ul style="list-style-type: none"> • Shared experience • Shared benefit • Shared involvement
Peer Support Worker Competency Framework for Mental Health (Royal College of Psychiatrists/ University College London 2020)	Values: An ability to understand that the peer support role is rooted in working alongside the person to develop an equal and trusting relationship, characterised by: <ul style="list-style-type: none"> • respect – being non-judgemental and not making assumptions about or pathologising the person's experiences or beliefs • reciprocity – a willingness to give and receive support, and learn from difference, with both parties sharing their experiences and benefitting from this • mutuality – a non-hierarchical relationship that is of equal value to both parties, and is based on shared experience of service use and recovery • An ability to draw on knowledge that peer support is: • non-directive – helping the person find solutions that work for them (rather than suggesting solutions) • strengths-based – focusing on and building a person's strengths and their ability to make use of the resources available to them • recovery-focused – creating hope and building autonomy, empowering the person who is being supported to define, lead and own their recovery, and enabling them to identify and work towards their life goals within their communities

As themes of shared experience, recovery, reciprocity, ownership and power are consistently identified as important features of peer support, these will be examined in more detail below.

2.5.1 Shared experience and experiential knowledge

In their consideration of what makes peer support unique, Mead and McNeil (2006:4) suggest that those who share similar experiences of mental or emotional

distress can offer 'more authentic empathy and validation'. Borkman (1976) argues that in a peer support context, understanding is based on the development of experiential knowledge; a truth that is learnt from first-hand personal experience rather than from discursive reasoning or information from others (professional knowledge). This is a 'critical component' (Borkman 1976:446) that distinguishes peer support from professional services. Borkman further argues that it is the holistic nature of experiential knowledge, and the 'cathartic dimension' it introduces, which allows individuals to feel understood and which promotes communication between individuals with similar experiences (Borkman 1976:450).

However, some debate surrounds who can be considered a 'peer' and therefore truly offer a perspective on a shared experience. Faulkner and Kalathil (2012:19-20) explore this question in detail, finding that for 75% of their 44 survey respondents, more than shared experience of mental or emotional distress was needed for someone to be considered a peer. Shared ideas of recovery, understanding of diagnoses and treatments were all identified as dimensions of shared experience which were viewed to be important, as well as common experiences of mental health services (being sectioned under the Mental Health Act for example). However more than 55% respondents also identified peers as those who shared gender, ethnic background, sexual orientation, age groups and faith and could understand cultural practices and religious needs. These findings demonstrate the complexity of peer relationships and the importance of understanding individual perspectives on who they consider a peer. Repper (2013:9), reflecting on these findings, argues that to be an effective 'peer' it is necessary to be able to contextualise experiences of mental or emotional distress in the communities within which they are experienced and that shared characteristics such as cultural background, religion, age or gender might all serve to make peer support more helpful (Repper 2013:4).

Seebohm, Munn-Giddings and Brewer (2010:25) similarly question whether individuals might prefer to be with those who share a similar background, rather than those with a similar mental health diagnosis, specifically those in Black and Minority Ethnic (BAME) communities. This is explored in the 2017 evaluation of the Side by Side Peer Support Programme through interviews and focus groups with 39 individuals from a BAME background. Importantly, it was found that alongside

experiences of mental or emotional distress, there were several other important areas of common experience that underpinned relationships in BAME specific peer support. These were: a shared cultural background, experience of migration, racism and discrimination and intersectional experiences. Overall, lived experience was such an important contributing factor to the experience of mental or emotional distress that it created a specific need for identity specific peer contexts for BAME groups (Billsborough et al 2017).

The role that perceptions of shared experience might play in facilitating peer relationships and connection in different peer support environments is not yet known. It has been suggested that the non-visual environment or anonymity of online peer support environments might be a factor in allowing greater disclosure and deeper connection as social factors such as race and physical attractiveness are neutralized and there is less likelihood of developing stereotypes or prejudice based on physical appearances (Walther and Boyd 2002). The ability to connect with very specific audiences and demographics through social media (for example a depression group for a very specific audience) could also enable individuals experiencing mental or emotional distress to tailor their peer engagement to others with very specific shared experience. As such, how ideas of shared experience differ across different forms of peer support is an area requiring further investigation.

2.5.2 Recovery

Writing in 1988, Deegan, a psychologist with lived experience of mental distress, talks of the importance of peer led groups and networks in supporting recovery.

Peer support does not seek to eradicate symptoms, or to place emphasis on the problems that an individual might be experiencing (Carter 2000, Bradstreet 2006, and Mead 2003). As such, it offers an alternative path to recovery to that offered by more traditional bio-medical interventions. Borkman (1999) argues that people come to peer support because they want to find a more positive way of resolving their problem, and that through participating in peer support, they are able to redefine the way in which they view and experience their condition:

‘People with stigmatised conditions need a liberating meaning perspective that can free them of self-hate, a negative self-identity, and assumptions that they are inadequate. They need to redefine their humanity. Moreover, they need a constructive way of dealing with their problem. A self-help/mutual aid commons exists in part to create a social space where people can freely define and evolve their own meanings and identity with regard to their shared problem, apart from the social groups or society that is devaluing them’ (Borkman 1999:115-116).

By focusing on an individual's strengths, peer support enables individuals to regain control over their own personal recovery. Mead and McNeil (2006), describe how simply by moving away from medicalised language and describing experiences in different ways (rather than using medical labels such as 'depression'), it is possible to facilitate a different type of conversation between peers, which in turn can lead to a different outcome/ coping strategy for an individual.

Survivor movements in mental health challenge assumptions that recovery is facilitated by professionals, and shifts the attention to what individuals themselves can do for themselves (Watson 2019a:10). As a non-professional intervention, peer support enables more holistic models of recovery which focus on personal journeys towards well-being (Khoury and Rodriguez Del Barrio 2015: i27) rather than treatment approaches which focus on symptom reduction.

The Scottish Research Network Narrative Research Project identified a number of elements that were important for the recovery process (Brown and Kandirikirira 2007). These included: hope and an optimistic outlook, holistic approaches that consider all elements of a person's well-being (rather than symptom management), enabling people to be active participants in their recovery, promoting self-management and coping strategies and an acceptance that experience of mental or emotional distress can give individuals new skills and experience with which they can support the recovery of others. Whether different forms of peer support contribute equally to such elements is an important question which is yet to be explored in the academic literature.

2.5.3 Reciprocity

Reciprocity can be understood as 'help that is freely given and received without calculation as to who gives how much or who gives the most' (Munn-Giddings and Borkman 2018:62). Ideas of reciprocity are often central to definitions of peer support, for example, Mead (2003) and Solomon (2004) talk about help that is 'mutually offered' or the 'giving and receiving of support'. The importance of reciprocity is based on Riessman's 1965 theory of 'helper therapy'. This argued that by giving support, individuals are able to develop a sense of competence by having a positive impact on another's life and gain social approval from both those they help and others. This was explored further by Skovholt (1974:62), who additionally proposes that the effective helper can feel an increased sense of interpersonal competence and sense of equality whilst also receiving social approval and valuable personalized learning. Munn-Giddings and Borkman (2018:62) argue that in a face to face peer group context, it is 'the criteria of reciprocity' that creates distinct helping relationships between participants, and that this can lead to individuals developing increased agency and new understandings of their situations. More attention will be paid to the potential benefits of such reciprocal relationships in the following chapter.

There is now some recognition that patterns of reciprocity play out differently across different forms of peer support. In their recent research, Billsborough et al (2017:4) found that the 'most change was achieved' for individuals when there was 'active giving and sharing of peer support in a two-way interaction'. Importantly, their findings also suggest that the roles of giver and receiver differ across different forms of peer support. Bracke, Christiaens, and Verhaeghe (2008) also bring an important contribution in asking at which point an optimum balance is achieved between giving and receiving support. However, there remains considerable scope for further exploring the nuances of reciprocity across different forms of peer support.

2.5.4 Ownership/ power

Faulkner and Bassett reflect that

‘As mental health service users we take each other’s stories seriously where often the professionals do not. Telling our stories and listening to each other’s stories is the cornerstone of peer support, empowerment and recovery. But it is also a political act’ (2012:5).

This statement gives a sense of the disempowerment sometimes experienced by individuals experiencing mental or emotional distress and the role that peer support can play in enabling them to reinstate a sense of power over their own recovery. Beyond the individual, face to face peer support groups also have formed an important part of the wider survivor movement in the UK in challenging traditional bio-medical approaches to mental health. Borkman and Munn-Giddings (2008) give the specific example of how individuals with experience of personality disorder used their participation in peer support groups to develop their understanding around their experiences, and to create a platform from which they could challenge and inform wider societal discourses around personality disorders. User-led groups (run for and by peers) in the UK tend to continue to value their independence from the mental health system (Faulkner and Kalathil, 2012).

However, the levels of ownership and control offered by peer support arguably depend on the structures themselves through which peer support is organised. In a user-led group, individuals might be responsible for running a group as well as attending, and facilitation is likely to be peer-led by existing members of the group. Self Help UK (a specialist organisation that promotes and supports self-help groups in the UK) advocate for such involvement, identifying the benefits that individuals can experience from being involved in running a group on their website:

‘Many groups share the responsibility for the group business, such as rotating the role of Chair, which leads to shared benefits.’ (Self Help UK 2020).

Such groups are largely open access, and new members do not need to fulfil any kind of eligibility criteria. This freedom is often important to smaller groups, who fear the restrictions that might be placed on them by formal commissioning arrangements (Faulkner et al 2013).

Peer support groups, especially those facilitated by national charities, increasingly receive funding or support from local clinical commissioning groups. In some cases, this has led to new eligibility criteria, such as a requirement to be registered with a GP in a specific geographic area and, in some cases, to be having 'mental health problems' managed by a GP. Other criteria state that you should already be in contact with mental health services or have a particular attitude towards your recovery, an example being a willingness 'to work on identified actions to assist them in achieving their stated goals and help towards them moving forward in their life' (Bromley, Lewisham and Greenwich Mind Peer Support Referral Form, Bromley, Lewisham and Greenwich Mind, 2019). Such statements suggest that peer support is being aimed specifically towards those who accept and are already in receipt of professional treatment services, underpinned by bio-medical conceptualisations of mental health.

Online, participants in peer support might also take different levels of ownership. Later in this chapter, I talk about the difference between the large online forums facilitated and moderated by large charities, and the online peer support which takes place through social media channels, which an individual can themselves set up and which is largely unmoderated. It is evident that levels of ownership and power are not consistent across different forms of peer support, however it is not yet well understood what the repercussions of this might be for those who engage with different peer support environments and whether opportunities to have more control and ownership have significant additional benefits, when available. Some academics argue that even the way in which individuals come to peer support in itself is important, with the choice to self-refer yourself (as opposed to being referred to a peer support group by someone else) forming part of individual recovery (Borkman 1999). In the online world, Naslund et al (2016) also argue that the independent choice made to engage with online peer support is a critical step in an individual's recovery.

2.6 A complex and evolving landscape

Earlier in the chapter, I introduced Bradstreet's 2006 categorisation of peer support into three activities: informal peer support, peer support that takes place within peer run groups/ programmes and formal peer support within mental health services. However, in the 14 years since Bradstreet proposed his categorisation of peer support, the peer support landscape has evolved in the UK to become increasingly complex. Two important reports demonstrate this complexity. In 2013, Mind published a report entitled 'Mental health peer support in England: Piecing together the jigsaw' (authored by Faulkner et al 2013). This report sought to map peer support provision in the UK and identified eight different types of peer support projects including self-help groups, formal approaches to peer support, recovery and intentional peer support, peer mentoring and online peer support (Faulkner et al 2013:14). In 2017, an evaluation of a Lottery funded programme 'Side by Side' was published (authored by Billsborough et al 2017). This was a partnership project developed by three large national charities, Mind, Bi-polar UK and the Depression Alliance and sought to increase access to community-based peer support for individuals experiencing emotional or mental distress. In all, this evaluation looked at 46 different peer support projects across England and identified seven different approaches and models: one to one peer support, peer support in groups, peer support online, user-led and grassroots models, peer support in mental health services, integrated versus complementary, and professionally vs peer led models of peer support. Whilst online peer support is mentioned in both reports, it is not the main focus and in the 2017 evaluation is largely based on Mind's 'Elefriends' forum (currently being rebranded as 'Side by Side').

Peer support is now available in a plethora of forms, from more traditional face to face peer support groups, to newer online contexts, with individuals connecting via apps and social media. Three trends have been particularly important in shaping the peer support landscape in the UK: social movements and the birth of single-issue group in the 1970s; technological developments since the 1980s and the UK policy agenda since the early 2000s. In the following section, I explain how each of these has played an important role in the creation of the UK's rich and complex peer support environment.

2.6.1 The service user movement and the birth of the single issue group

Arguably it was in the 1970s that peer support (then more often referred to as self-help) first emerged onto the mainstream agenda in Western Europe in the form of single-issue groups (Shaw 2014). The 1970s saw the birth of a number of social movements which championed gay rights, the rights of women, disability rights and which brought individuals together in collective action in a way that had never been seen before. These wider social and political changes created a greater emphasis on individual empowerment and aspirations to end discrimination and are argued to have led to the establishment of groups such as the Mental Patients Union in 1973 (Wallcraft, Read and Sweeney 2003:14). Some accounts suggest that it was an experience of mental health difficulties as a 'lynchpin' for activism that brought people together (Faulkner and Basset 2012:55). However, others suggest that it was wider social movements, such as the women's movement, that first led to a recognition of common experience and which then led to women deciding to join self-help or peer support groups (Rapping 1997).

Significant challenge began to develop from these campaign groups with regards to how mental health was both understood and treated. A new social model of mental health emerged, which recognised the role that social factors play to experiences of distress (Faulkner and Bassett 2012). Dawney (2011) highlights the way that during this period, 'experiential' knowledge began to challenge the professional, scientific knowledge which had come to dominate discourses of mental health.

In the early 2000s, two publications sought to understand the number of peer support groups in the UK in different ways. In 2000, Elsdon counted the number of self-help groups (across all conditions) in the Nottingham Health Authority Area and extrapolated this number to estimate the number of groups across the UK, suggesting that there might be around 23,400 self-help groups in the U.K, with their overall membership representing 2.64% of the UK population. However, Elsdon's extrapolation methodology is problematic as it assumes all areas to have a similar concentration of groups as one Health Authority Area, which is not known to be the case. Elsdon (2000:6) also finds the number of self-help groups to be rising, and estimates this growth to be at an average of 9% per annum since 1982. In 2003, Wallcraft, Read and Sweeney undertook a detailed mapping exercise to better

understand both the scale and nature of mental health user groups and created a database of 798 groups. They then conducted a survey which received 318 responses after sending out a questionnaire to the full database. This study provides several useful insights into the nature of the activities undertaken by such groups in the UK, such as the scale of peer support activity taking place, with 79% of the groups surveyed said that they facilitated self-help and social support. This was in fact the main cited activity, above consulting with decision makers, education and training, campaigning and advocacy work. Wallcraft, Read and Sweeney (2003) also found that there had been an increase in the number of groups being set up; 42% groups responded that they had been set up in the last five years rising to 75% in the last ten years and 89% in the last fifteen years.

Munn-Giddings (2003) draws attention to the lack of distinction between groups set up to facilitate service user involvement and user led groups in the Wallcraft study and it is important to recognise that the emergence of new groups in the late 1990s to early 2000s can perhaps be partly attributed to government policy which has increasingly promoted user involvement in services. Campbell (2005:74-75) goes so far as to say that some groups 'have been created solely to meet this demand' and that this demand has been important both in stimulating the growth of groups as well as influencing the activities they undertake. Writing 9 years ago Loat suggests that it is an increasing alienation in the modern world which causes people to continue to seek out support in a group setting:

'over the past three decades, the industrialised world has seen a steady increase in the number of people who turn to mutual support groups and organisations to help them cope in times of need' (2011: 23).

Several recent sources suggest that numbers of smaller user-led groups have declined in the last five years. A briefing note, produced by the National Survivor User Network (NSUN in 2019 looks specifically at user led groups and cites three sources of data that illustrate this shift. Firstly, a review of NSUN user groups found that 158 groups had closed in 2016/7 and 55 groups had joined its network. This was in comparison to another earlier approximate 18-month period in which around 20 groups had closed and these had been replaced by a similar number joining the network. The briefing also identified that the user-led network 'Shaping Our Lives'

had also removed 124 user led organisations from the national network (NSUN, 2019). The NSUN briefing note also cited evidence from the 2016 NCVO Civil Society Almanac that confirmed both 'the number and proportion of small organisations is decreasing'. This trend continues, with the 2020 Charity Almanac stating that micro and small organisations had made up 88% of the overall voluntary sector in 2000/01 but that this had fallen to 81% in 2017/18. NSUN cite a number of reasons for this decline, including years of austerity and reduced funding for the voluntary and community sector, the limits of individual capacity to run and support groups, and competition from larger charities which increasingly adopt the language of a user led approach (NSUN, 2019).

Whilst, as this section has illustrated, numerous efforts have been made to map and capture the number of face to face peer support groups in the UK, it is important to stress the difficulty in accurately capturing the activity of small grassroots organisations, which can exist under the radar. Recently this has been demonstrated by a 2020 report from the Local Trust which uses 360°Giving data to identify groups receiving grants from UK foundations but which might not be identifiable by other means (such as charity registration). Importantly, the report recognises that even using this data will only capture one further sub-section of grassroots groups in the UK, as numerous other groups exist which do not access this type of funding (Local Trust 2020). Despite new efforts to share and use data, it remains difficult to measure in a definitive way the scale of groups that are currently operational in the UK, and the ease, or difficulty with which individuals seeking this form of peer support are able to access them.

2.6.2 Technological Developments

Technological developments that have taken place since the late 1990s, such as the introduction of web discussion forums, have facilitated new forms of online peer support (Faulkner et al 2013). In 2006, King and Moreggi estimated that thousands of self-help groups already existed on the internet, devoted to a wide range of conditions and with varying levels of activity. It is possible to divide forms of online support into several broad categories:

Online bulletin boards and moderated forums

Firstly, a number of moderated online forums/ online bulletin boards have been set up and continue to be hosted by several large UK Mental Health Charities. These include:

- The Bipolar UK eCommunity <https://www.bipolaruk.org/ecommunity>. Over 5,000 members.
- The SANE Support Forum ([www.sane.org.uk/what we do/support/supportforum](http://www.sane.org.uk/what_we_do/support/supportforum)).
- 'Elefriends', hosted by Mind (www.elefriends.org.uk/). Started life as a Facebook group but has been facilitated by Mind since 2013. It is now being transitioned to a new online platform called 'Side by Side'.
- The Mental Health Forum (www.mentalhealthforum.net). Started by the Mental Health Foundation in 2003 and now run by volunteers with support from the non-profit organisation, Together 4 Change. As of the 14th August 2020, it had 69,659 members.
- The Black Dog Tribe ([www.sane.org.uk/what we do/bdt/bdt blogs](http://www.sane.org.uk/what_we_do/bdt/bdt_blogs)): started by Celebrity Ruby Wax and now run by SANE.
- <https://www.beateatingdisorders.org.uk/support-services/online-groups> (online forums where access is only possible at specific times, when moderation is available).

Some of these forums allow their content to be open to the public (SANE, Mental Health Forum) whilst others are inaccessible without registration. To post on any of these forums you must be over 18 and register as a member. Some mental health peer support forums are targeted towards certain demographics, such as those set up for university students (one example being Horgan, McCarthy and Sweeny 2013).

Social media and social networking sites

There are now approximately 45 million active social media users in the UK, representing 66% of the overall UK population (We are Social 2020). Platforms such as Facebook (launched in 2004) and YouTube (launched in 2005) are estimated to

reach around 60% of the UK population, with more recent applications, such as Instagram (launched in 2010) reaching around 30% (Statistica 2020). Naslund et al (2020:425) argue that social media has now become a 'prominent fixture' in the lives of individuals experiencing mental or emotional distress and an important way in which they reach out to others. A simple search on Facebook reveals the hundreds of online peer support groups available on an incredibly diverse set of mental health topics and with membership numbers ranging from several hundred to hundreds of thousands. One important difference to the online bulletin boards hosted by national charities is that groups on social media platforms tend to be subject to less moderation and tend to be run by peers for peers.

Several studies have sought to understand how individuals with experience of mental or emotional distress engage with social media or social networking sites. Gowen et al (2012) surveyed 274 Australian University students, finding that 94% of participants with experience of mental or emotional distress were using social networking sites and that those individuals were more likely than those without such direct experience to engage in social networking activity which promoted developing online friendships and connectivity. However, the authors recognise the limitations of using a convenience sample in this study, which can only serve to provide an indication of the experience of a very specific age demographic. Miller et al (2015), looking at the wider question of how individuals with schizophrenia connected with others, surveyed 80 patients aged 18-70, asking how frequently they used a mobile phone, text messaging, email and social media. In this wider age demographic, a far smaller number of participants (27%) reported using social media sites daily. Finally, in a study involving 26 semi-structured interviews with individuals with clinical diagnoses of depression, 14 described using chat rooms or networking sites (Schrack et al 2010). Using data collection methods such as content analysis, academics have also started to explore how uploading videos and responding to comments on social media channels such as YouTube have started to create new avenues for forms of naturally occurring peer support for individuals with experience of mental or emotional distress (Naslund 2014).

Use of social media by face to face peer support groups

Thirdly, research has shown that online peer support is also used in conjunction with face to face group peer support. Boyce et al (2014) explore the use of social media by self-help groups, finding that many employed mediums such as electronic mailing lists, websites or Facebook groups and that they offered both group and individual benefits. For groups, online mediums were a way to attract new members, keep members informed and updated and to keep costs down. For individuals, the additional online support offered in conjunction with face to face groups enabled individuals to feel supported and connected and to engage in peer support according to their personal needs (with some members preferring to receive online communications rather than attend a face to face group). Boyce et al (2014) suggest that the traditionally drawn lines between different forms of peer support are becoming somewhat superficial as face to face peer support groups start to use online mediums in addition to face to face meetings. As such there is an increasing blurriness between the boundaries that have traditionally demarked different forms of peer support. However, the interplay between different forms of peer support is not something which has largely featured to date in the academic literature and as such, this highlights how much is still unknown about how different forms of peer support are used in combination.

2.6.3 Individualisation and peer support in recent UK mental health policy

In 1999, the Department of Health introduced the National Service Framework for Mental Health Services. This advocated patient involvement in the planning and delivery of services, emphasising the fact that involvement in planning services leads to better care and outcomes. It also drew attention to the fact that despite an appetite for involvement, many users of mental health services still felt excluded. (National Service Framework 1999:43). The framework also made direct reference to the value of self-help groups for those experiencing mental health difficulties (National Service Framework 1999:23). Shaw (2014) argues that this saw the beginning of a policy movement which aligned peer support closely with ideas of personalisation, recovery and self-management and identified peer support as a key mechanism to transform mental health services.

This positioning of peer support within services can be argued to have been one factor that has led to the growth of peer support workers within mental health services in the UK, and follows the development of consumer provided mental health services in North America (Watson 2019a). Repper (2013) highlights the rapid growth of peer support workers from 2010 – 2013, from virtually no presence at all in 2010 to being present in several health trusts by 2013. Peer support workers were seen to be a way to drive a recovery focused approach within mental health services and to challenge assumptions from those without lived experience of mental distress (Repper 2013). Their introduction was also seen as a way to fill skill gaps in mental health teams (Gillard and Holley 2014).

However, there is concern that the enthusiasm for the individualised model of a peer support worker approach has detracted from other forms of peer support and promoted a model of one to one support above group-based support or support based in community settings. Basset et al (2010:11) question the lack of 'a shared agenda or solidarity' in the personalisation agenda, arguing that this is essential to achieve the potential benefits of peer support:

'it is most often a collective sense of being in the same boat with accompanying solidarity and empowerment that forms the basis of peer support and is very important in enhancing individual support and benefits' (Basset et al 2010:11).

Munn-Giddings et al (2016) similarly warn that this approach could be to the detriment of community-based peer support groups, with understandings of their unique contribution being lost. Finally, the context of austerity risks all forms of peer support being viewed as a cost-effective alternative to other forms of support (Watson 2019c).

Community-based peer support has not necessarily been forgotten. The 2011 Mental Health Strategy for England 'No Health without Mental Health' clearly recognised the role that local voluntary and community organisations could play in supporting individuals experiencing mental or emotional distress:

‘... local voluntary and community organisations can draw on the wealth of experience of their local communities in meeting the needs of groups they work with, including those groups most excluded and/or experiencing poor mental health. Some of these organisations have experience of helping people to manage their own mental health better in the community – including through peer support services, user-led self-help groups, mentoring and befriending, and time-banking schemes, which enable service users to be both providers and recipients of support’ (2011:35).

Funding has been awarded to develop community peer support through initiatives such as the 2012 Social Action Fund and the 2014 NHS forward view continued to stress the importance of ‘stronger partnerships with charitable and voluntary sector organisations’ (2014:14). However, despite such statements of support, approaches to peer support across different sectors remain fragmented. Local authorities, who often fund smaller community-based peer support initiatives, have seen their spending reduced by £16 billion pounds since 2010 (Local Government Association, 2018) and funding reductions have had a direct impact on the support available to the voluntary sector:

‘Councils now spend less on early intervention, support for the voluntary sector has been reduced, rural bus services have been scaled back, libraries have been closed and other services have also taken a hit’ (Local Government Association 2018:6).

A 2016 report from the Independent Mental Health Task Force to the NHS makes the strong statement that:

‘Everybody in mental health services should be able to say ... I am provided with peer support contact with people with their own experience of mental health problems and of using mental health services. I can find peer support from people who understand my culture and identity. Peer support is available at any point in my fluctuating health – in a crisis, during recovery, and when I am managing being well’ (2016:37)

It is important to question exactly what kind of peer support is being talked about here, whether all forms of peer support are being valued and promoted, and not to lose the important recognition that not all those accessing peer support choose to access mental health services.

2.7 International Perspectives

The comparative evolution of peer support in other nations indicates the important role of the welfare state and national health policy in determining the form and availability of peer support (Munn-Giddings and Stoeken 2012). Reflecting on how social governance, health care and civil society have shaped self-help/ mutual aid and peer support in Europe, Munn-Giddings and Boyce (2020) argue that by taking an approach that considers peer support within different national contexts allows a new appreciation of how the principles of peer support can be shaped, or indeed distorted, to fit different socio-political agendas. In their consideration of Bismarckian, Mediterranean, Socio-democratic, Post-communist and Liberal Welfare States, they find differences both in relationships between government and self-help organisations, and in understandings of peer support itself. Examples are given of countries such as Germany, where peer support activities are state funded through health insurance monies, resulting in a network across the country, in stark contrast to the somewhat fragmented peer support network in the UK. Peer support in Germany is also situated as a complement to professional health services rather than as an alternative or challenge. Norway is a further example of a country which has chosen to invest nationally in peer support, and developed a national plan for self-help in 2004 (Hedlund, Landstad and Tritter 2019). However, this has also resulted in increased surveillance and bureaucracy, with group members being asked to sign a formal confidentiality agreement before attending groups (Hedlund, Landstad and Tritter 2019). Whilst the national plan and funding have enabled self-help groups to become an established part of the welfare state in Norway, Hedlund, Landstad and Tritter (2019) question whether such state involvement has led to the professionalisation of self-help groups to the extent that they no longer empower their members in the same way, but instead are used as a solution for medics for 'Heart Sink Patients' who have not responded to professional treatment. These examples demonstrate the complex interplay between professional mental health

services and peer support as well as how peer support as a concept and practice is understood in different country contexts.

2.8 Chapter summary

The last fifty years have seen dramatic changes to the peer support landscape in the UK. In 1970, an individual might have had the option of joining a recently formed single issue group to talk about their experiences of mental or emotional distress. Now, a myriad of options are potentially available, facilitated both by new technologies and mental health policy that has introduced new 'formal' forms of peer support. The growth and endurance of peer support in the UK demonstrates how this form of support continues to be important for individuals experiencing mental or emotional distress. However, it also raises new questions about the unique contribution of each form to individual well-being and whether different forms of peer support are always used in isolation, or in fact, if individuals call on individual forms of peer support in response to specific needs or use different forms of peer support in combination.

As forms of peer support in the UK have become more complex, researchers have responded, and there is now significant literature that looks individually at outcomes from participating in online support groups, face to face peer support groups and formal one to one support relationships. However, forms of peer support are almost always considered in isolation. The findings of Boyce et al (2014) hint at how forms of peer support are now being used in combination and this creates a need to look across different forms of peer support. For me, such a pluralistic approach to peer support creates an opportunity to understand how key features of community-based peer support such as reciprocity, shared experience, ownership/power and recovery play out in different peer support environments. I have also found the recent literature base to be predominantly focused on formal peer support, alongside a lack of clarity in policy initiatives around whether they encompass community as well as formal or intentional forms of peer support. Accordingly, this study will focus on community-based peer support, which arguably has received less attention from the academic community, despite playing such an important role in the initial development of peer support in the UK.

Finally, I argue for the importance of considering the unique social-political factors that shape national landscapes of peer support. I argue that in the UK three trends have been particularly important: the rise of single-issue groups following the social movements of the 1970s, technological developments and UK health policy that has favoured individual rather than collective responses to well-being and health. The legacy of these trends can be seen in the definitional challenges around peer support and the way in which the terminology surrounding peer support are infused with different nuances. As peer support evolves, there is some concern that the values from the grassroots movements that first popularised peer support will be lost.

The increasing complexity of the peer support landscape in the UK raises new questions around how individuals with experience of mental or emotional distress use peer support to enhance their well-being. In the next chapter, I will look at the motivations for individuals to engage in different forms of peer support and what is already known about the benefits and limitations of different forms of peer support, as well as the different frameworks through which peer support is evaluated.

Chapter Three

Engagement with peer support and outcomes

3.1 Introduction

Having established the complexity of the peer support landscape in the UK in the previous chapter, in this chapter I move on to examine what is already known about how individuals engage with different forms of community-based peer support (online, face to face group and one to one) and how the outcomes from this engagement have been explored and conceptualised.

I begin the chapter by considering the existing literature that explores why and how individuals engage with different forms of peer support. Within this, I appraise what is already known about how motivations and patterns of participation are similar or different across forms of peer support. I then identify and explore two frameworks which can be employed to consider the outcomes of engaging with peer support. Firstly, treatment evaluation perspectives, through which the effectiveness of peer support is judged on the extent to which it can enable an individual to reduce clinically assessed symptoms of mental illness. Secondly, well-being perspectives, which are based on the standards or values that people themselves seek and their subjective realities or judgements of their lives. I argue that well-being perspectives offer the researcher the opportunity to understand the intentionality and agency with which individuals first seek out and then use peer support, and as such, how different forms of peer support ultimately contribute to individual well-being in a way that has personal meaning.

Having identified these frameworks, I examine the existing empirical data on the processes and outcomes that have been identified from studies of community-based peer support. These are divided into studies that focus on symptom reduction, and studies that focus on contributors to individual well-being, such as levels of social support, reciprocity and self-esteem. This leads me to conclude the chapter by identifying a clear gap in knowledge; whilst numerous studies examine outcomes from engaging in individual forms of peer support, there is comparatively little understanding of how different forms of peer support are used in combination or sequence. As such, more research is needed to better understand the nuanced

ways in which online, face to face group and one to one peer support can contribute to individual well-being.

3.2 Why individuals use peer support

In this section, I explore what is already known about why individuals engage with different forms of peer support. Firstly, I consider the motivating factors that might lead an individual to engage with peer support. I then reflect on the accessibility of different forms of peer support and how referral or signposting by health professionals might influence decisions around engagement.

3.2.1 Motivations

I encountered several challenges in my exploration of the existing research on what might drive individuals with experience of mental or emotional distress to seek out peer support. Firstly, motivations for engaging with different forms of peer support are often considered as part of a wider research brief looking at processes or outcomes from peer support, rather than as a stand-alone area of investigation. Secondly, the terminological complexities covered in the first chapter of this thesis, and need to ensure inclusion of studies using such terminology as ‘support groups’ and ‘self-help/mutual aid’, as well as different understandings of what peer support is, and how an individual might come to use it, added further complexity. Later in this chapter, I talk about the underlying assumptions of treatment evaluation studies and how such studies do not generally consider personal motivations for individuals accessing peer support. Finally, I specifically wished to understand what was already known about why individuals came to peer support in the first place, but found it was often difficult to unpick initial drivers from the reported benefits of attending a group, after a period of participation. These challenges all demonstrate the important, but complicated, nature of pluralistic approaches to peer support.

Looking beyond the literature that focused solely on individuals with experiences of mental and emotional distress, to the use of peer support for a number of different circumstances, raised a number of interesting insights. A first consideration is whether individuals use peer support because they are unable to access other forms of support, either from family, or professional health services. Munn-Giddings

and McVicar (2007) find that loneliness was a key motivation leading carers to access face to face peer support groups. Individuals described how their existing support networks were unable to support them in their caring roles, and this led them to seek out others with similar direct experience. Ussher et al (2006) identify a similar experience for individuals accessing cancer support groups, with some participants describing family or friends as being dismissive of their illness or, in more extreme cases, feeling rejected or abandoned by those closest to them. Interest in attending a face to face peer support group, therefore was fuelled by a desire for acceptance and belonging. The stigma associated with experiences of mental or emotional distress in the UK is well-known, and led to the national 'Time to Change' campaign to reduce stigma and discrimination in 2007. As such, it is reasonable to suppose that feelings of loneliness and stigma are also reasons why individuals with experience of mental or emotional distress might seek out peer support in this form.

A second important consideration is whether individuals with experience of mental or emotional distress seek to use peer support alongside professional health services or as an alternative. Accessibility can be considered in terms of being able to physically access primary or secondary clinical services, but also in terms of bio-medical conceptualisations of experiences of mental or emotional distress and whether these are compatible with personal explanations. Dillon and Hornstein (2013:289) offer a useful perspective on how hearing voices peer support groups can offer wider understandings of experiences of mental or emotional distress than those offered by traditional psychiatric approaches:

'HVN explicitly accepts all explanations for hearing voices, and encourages people to explore their own beliefs, be they spiritual, religious, paranormal, technological, cultural, counter-cultural, philosophical, medical, and so on'.

The extent to which peer support is used as an alternative or complement to professional mental health services is not understood in its entirety and is related to the welfare systems in which peer support develops. As such, this is an important area of future research.

The high profile of peer support and increasing interest in its potential to help individuals in the UK as part of the wider welfare landscape is clearly evident from the fact that it was chosen as the focus for the first project for an NHS improvement initiative 'The Q Improvement Lab' from April 2017 to May 2018. The 'Q' was established in 2015 in response to the recommendations from a 2013 report from the National Advisory Group on the Safety of Patients in England. This report stressed the need for continual learning and improvement within the NHS, and the need for both more joined up approaches and greater capacity for the 'top to bottom' of the NHS (National Advisory Group on the Safety of Patients in England 2013:10).

For project one, entitled 'Peer support available for all', a nationally-representative survey was undertaken with 2,666 participants in the UK. This sought to understand the perspectives of three groups; health care professionals (n=619), members of the public with experience of long-term conditions (n=986), members of the public without long-term conditions (n=848) and peer support workers (n=96). The findings from the survey suggested that 20% of the public had experience of using peer support and that those with a long-term condition were twice as likely to have used peer support. It was also found that women and those over 65 were also more likely to have used peer support (Q Improvement Lab, May 2018). Nationally representative surveys such as this are rare in research around peer support and as such this survey provides a broad insight into prevalence of peer support across the UK. However, the macro level of the reporting means that numerous questions remain around the experience of individuals with different long-term conditions, how expectations vary when it comes to different pathways into peer support and the experiences of different sectors of the population. Several of these further areas of research are noted by the researchers themselves.

The Q Improvement Lab survey also sought to understand why individuals may or may not have accessed peer support and asked participants to rank a list of twelve possible factors which might lead them to access peer support, in order of importance (Q Improvement Lab, May 2018). For those who had not yet accessed peer support, the three factors identified as the most important were a belief that peer support would help, trustworthiness (defined as safe, confidential and high quality) and accessibility (defined as quick and easy to access). For those who had

already accessed peer support, the opportunity to meet people with similar experiences was also considered to be extremely important, alongside accessibility and a belief it would help (Q Improvement Lab, May 2018).

Whilst this survey provides a useful indicator of motivations for accessing peer support in the UK, it is important to note that it did not focus specifically on individuals with experiences of mental or emotional distress, nor does it distinguish between different forms of peer support. By asking individuals to choose from a menu of reasons to describe motivations, it also did not allow participants to come forward with their own reasons for engaging with peer support, in their own words. Within the menu of possible motivations included in the survey, two statements also illustrate the very specific perspective from which peer support was being viewed. Participants were asked whether 'the service being endorsed by a health care professional' and 'reducing burden on the NHS' were important considerations for them. Such statements position peer support as a potential cost-effective alternative to accessing other health support services and suggest the need for approval from health care professionals before accessing peer support. As such, they invite questions around ownership and power, introduced in the previous chapter of this thesis.

The National Lottery Funded Side by Side Evaluation (Billsborough et al 2017), conducted by the McPin Foundation and St George's Hospital, provides a more in-depth analysis of why individuals with experience of mental or emotional distress chose to access community-based peer support. Using peer support logs in which 786 participants contributed insights over a period of up to one year (although it is noted that the number of logs tailed off as the evaluation progressed) and 69 qualitative interviews, participants were able to express their reasons for accessing peer support in their own words. This study found a number of useful findings including that:

'People chose to engage with different approaches to peer support for different reasons and at different times. In other words, engaging with peer support was purposeful, in response to a range of needs and aspirations including: a desire for meaningful activity; a need for social contact; sometimes referred by mental health services but sometimes to

address a gap in services; as a space to share experiences of mental health difficulties and strategies for coping; and sometimes responding to a crisis' (2017:23).

In specifically trying to understand why individuals might have come to one form of peer support over others, the evaluation does not explicitly attribute specific motivations to individual forms of peer support. However, the illustrative examples given for participants who described engaging with peer support because of a desire for meaningful activity, to address loneliness or as a space to share, all focus on face to face group support. Interestingly, one key difference between the forms of peer support was that participants especially (although not exclusively) turned to online support in times of crisis (Billsborough et al 2017). Although comprehensive and offering a useful perspective across different forms of peer support, this evaluation focused primarily on, and recruited from peer support projects delivered by three national charities; Mind, Depression Alliance and Bipolar UK. Therefore, the findings might not necessarily be representative of individuals accessing smaller grassroots or user led organisations, or online platforms that exist outside of this sphere.

In this section I have demonstrated that whilst several studies have examined the motivations for why individuals engage with different forms of peer support, it is not yet possible to explicitly assess why they might choose one form of peer support over another. A number of other factors are also likely to contribute to the type of peer support that individuals' access and it is to these I now turn.

3.2.2 Accessibility

It could be assumed that people will turn to whatever form of peer support is most accessible to them. Various factors mean that different forms of community-based peer support may not be accessible, or be less available, to some individuals. Watson (2019c:48) suggests that accessing face to face group support might be more straightforward than (formal, community-based) one to one peer support, given that there are more spaces available. This is explored in brief in the Side by Side Evaluation which finds that the training required before being able to access some formal one to one peer support is one specific challenge to accessibility

(2017:214). However, as outlined in the previous chapter, face to face peer support groups only exist where resources and interest permit and groups have faced increasing funding challenges in recent years. Because of the often-hidden nature of face to face groups, it remains difficult to accurately assess how accessible groups might be in the UK.

For those living in more remote or rural locations, online peer support might be more accessible than a face to face group or one to one peer support. In an Australian based study, Smith-Merry et al (2019) conducted semi-structured interviews with 17 users of an online mental health forum. Thematic analysis of the data demonstrated that participants had chosen to engage with online peer support to address feelings of both social and geographic isolation, to seek out social connection and for information and practical advice. Whilst geographic isolation may be more extreme in a country such as Australia, it is possible that similar geographic isolation is experienced by individuals living in less populated areas of the UK. This is suggested by participants in the Side by Side programme, who reported that Elefriends (an online peer support platform facilitated by Mind) was particularly important to them because they lived in more rural areas (Billsborough et al 2017:215).

Physical health has also been identified as a potential factor influencing what forms of peer support individuals choose, or are able to access. Davidson, Pennebaker and Dickerson (2000) examine the prevalence of face to face and online support groups in four large American cities across 20 different patient populations. They find the highest levels of online activity for conditions such as multiple sclerosis and chronic fatigue, leading them to suggest that online support is particularly attractive for those whom 'getting together physically would present a number of practical barriers' (Davidson, Pennebaker and Dickerson 2000:211). Tanis (2008), in an effort to explore the 'big attraction' of online health forums, conducted a survey with 189 respondents, finding complexity in the way features of online peer support, such as anonymity and accessibility, are appreciated by users; with those feeling most stigmatised seeking the former and those restricted in mobility the latter.

Social barriers may also differ when it comes to different forms of peer support. Authors such as Dow (2011) and Memon et al (2016) discuss the cultural beliefs

and values that can prevent migrants, or individuals from a BAME background from accessing mental health services and it is possible that these also impact on the propensity of such groups to access peer support. Writing in 1997, Borkman found a disproportionate presence of white middle class females in self-help groups in the US (Borkman 1997). More recently, the Side by Side Evaluation conducted focus groups and interviews with 39 individuals who had accessed BAME specific peer support. Experiences of migration, racism and discrimination, as well as intersectional experiences, were identified as important factors in determining who individuals felt to be a peer with shared experience (Billsborough et al 2017). As such, BAME individuals may feel a non-BAME specific face to face peer support group to be ill-equipped to understand their lived experience.

Naslund et al (2016) argue that online peer support networks are the only way to access the most isolated members of society. Whilst digital literacy was once identified as a significant social barrier, it has declined significantly in the last ten years. However, it remains an issue for some, with 7.5% of the adult population in the UK, still identified by the Office of National Statistics (ONS) as 'internet non users' (Office for National Statistics, 2019). This is defined as individuals who have never used the internet or who have not used it in the last three months (ONS 2019). The Lloyds Bank UK Consumer Index (2020) examines the digital skills of the UK population in more detail, finding that an estimated 9 million people were unable to use the internet and a device by themselves.

3.2.3 Referrals and signposting

Choosing to access face to face group or online peer support has been argued, in itself, to be an important step in the recovery process (e.g., Borkman 1999, Naslund 2016). As such, another important consideration is whether individuals come to different forms of peer support as the result of a personal decision or referral from a healthcare professional, and whether health professionals are more likely to refer individuals to one form of peer support than others. A survey from the Q Improvement Lab (n=619) offers some insight into the scale at which health professionals were currently referring individuals to peer support in the UK, with around 38% of general practitioners and over 50% of mental health care workers self-reporting that they had referred service users to peer support (Q Improvement

Lab, May 2018). However, these results do not tell us to which form of peer support professionals were referring or whether such referrals resulted in individuals engaging with different forms of peer support. As previously mentioned, the Q Improvement Lab study also did not distinguish between peer support offered for long-term health conditions or experiences of mental or emotional distress. It is also possible that professionals were signposting to peer support rather than making written referrals, meaning that individuals might go on to self-refer themselves.

It could be assumed that health professionals are making more referrals to peer support groups or organisations as the profile and understanding of peer support grows in the UK. The 2017 Evaluation of the Side by Side Peer support programme identifies that for some, it is a referral from a health professional that has led them to first engage with peer support. However, the report also stresses the very many different reasons and pathways which lead individuals to peer support (Billsborough et al 2017). Due to the siloed nature of the literature on peer support in the UK, very little is known about the pathways between different forms of peer support. As such, this remains an area of interest for future inquiry.

3.3 Patterns of participation and engagement

In this section, I turn my attention to whether patterns of participation and engagement differ across the various forms of peer support. The following aspects of participation are explored in brief: frequency and length of engagement, active or passive participation and the reasons for withdrawing from, or ceasing engagement with, different forms of peer support.

3.3.1 Frequency and length of engagement

Several studies on face to face group peer support and online peer support recognise that more regular engagement with peer support is associated with better outcomes (e.g., Behler et al 2017, Houston, Cooper and Ford 2002, Markowitz 2015). However, it is not definitely known whether individuals with experience of mental or emotional distress engage with specific forms of peer support with more regularity, or for longer than others. Generally, information on the length of engagement is reported inconsistently across the literature, with systematic reviews

and RCT trials (e.g., Houston, Cooper and Ford 2002, Pistrang, Barker and Humphreys 2008, Lloyd Evans et al 2014) recording outcomes at 6 and 12 months, but providing no insight into possible benefits or outcomes from engagement with peer support beyond this point. For Behler et al (2017), such restrictions are unhelpful; in their study the authors note that the average period of time attending a face to face peer support group was far longer, at 6.6 years. The complexity of engagement even over a twelve-month period is captured in part by the 2017 Side by Side evaluation, which starts to consider engagement across different peer support projects (and potentially different forms of peer support):

‘These figures are restricted to 12 months as there is very little data after that point. It can be seen that the number of projects attended by participants (in the previous month) over the course of the study decreases very slightly ... from an average of just over 1.5 to just under 1.5 projects... it appears that participants were on average receiving and giving peer support in 2.5 different forms, this dropping to 2 forms by month 5 and continuing to drop to 1.5 different forms by month 11’ (2017:54).

Some consideration has been given to the optimum length of time for which an individual should use peer support. Contemporary funding restrictions mean that individuals engaging in community peer support projects might now be encouraged only to attend a face to face peer support group for a year or to access a fixed number of one to one peer support sessions. Such restrictions could be justified by trying to provide a service to as many people as possible with limited resources, but potentially also stem from a concern that individuals with experience of mental or emotional distress might get ‘stuck’ in peer networks that isolate them from the wider community. Academics such as Borkman (1999) reject the premise that long term attendance of a self-help group is associated with a lack of recovery, arguing that participation in such groups is marked by numerous development stages and on-going, sometimes repeated patterns of learning:

‘In a developed group one sees a range of longevity from the newcomer to the veteran. Even among people at the same stage, the salient concerns and issues for individuals will vary depending on their biography, worldview, values, current circumstances, and so forth. Furthermore, variation occurs

because individuals learn at their own pace and troublesome aspects of the shared problem differ for each. As individuals participate over time, the four-phase cycle of experiential-social learning is repeated and can result in changes of behavior, or in some cases transformation of identity and lifestyle' (Borkman 1999:152).

Patterns of participation in terms of length and frequency of engagement across different forms of peer support are not currently well understood. If more frequent, and potentially longer-term engagement are more beneficial to individuals, then it is important to develop a better understanding of how online, face to face groups and one to one peer support relationships facilitate different patterns of engagement and the repercussions of this.

3.3.2 Active and passive participation

Participation in peer support can be considered active or passive. It is possible to attend a face to face peer support meeting and choose just to listen, to share your experiences or to progress to become a facilitator of a group. Online, you can choose solely to read comments, or to share information or to provide emotional support to others. Even in informal one to one relationships, there is the option to actively seek to provide support to a peer or to more passively receive support when it is offered. A pluralistic approach to peer support starts to ask if similar patterns of participation are replicated across different forms of peer support. Two studies looking specifically at aspects of online engagement offer a useful insight into this. Firstly, van Uden-Kraan et al (2008) compare outcomes for individuals who 'lurk' in online forums, against those who actively post content. They find benefits for both but that additional benefits are derived from those who participate more actively online. Carron-Arthur et al (2016), undertook a topic modelling exercise of the content in a mental health internet support group, finding that a small number of users post the majority of content. The authors stress the importance of super users or peer leaders online and point to considerable differences in the participation patterns of different members.

It is interesting to consider whether 'lurking' is a form of participation that is unique to online support and whether in face to face group settings, discussions might also

be dominated by the 'super-users' as they are in an online setting. There is recognition that in a face to face peer support group setting, patterns of participation may change over time, with newer members gaining confidence and contributing more (Borkman 1999). Vishram et al, members of a cancer face to face peer support group themselves, describe how many members 'arrive in crisis, barely able to voice their pain, but over time they feel better, look better and have a totally different perspective on their situation' (2012:143). Their comments suggest how participation of members may become more active over time.

Munn-Giddings (2003) offers a further useful insight into the different outcomes experienced between active and passive users of a face to face peer support group for carers. Semi-structured interviews with 15 active members (active here defined as regular attendance at meetings) and 5 members who did not attend meetings but did receive the group newsletter, revealed significant differences between the two groups in terms of how they interpreted their situations. Those attending regularly drew on their experiential exchanges with others to develop new expectations of what it meant to be a good carer in line with the lived experience of their peers, whilst those just receiving the newsletter had views on caring that tended to reflect dominant understandings expressed in the caring literature.

Whilst these studies provide useful insights into participation in different peer support environments, much is still not known about whether different forms of peer support facilitate similar peer support journeys from passive to active participation or how imbalances in participation of group members influence the overall experience and value of peer support to those engaging. As such, questions around active and passive participation in different peer support environments remain an interesting research consideration.

3.3.3 Withdrawing from peer support

A small number of studies have sought to understand why individuals have ceased accessing peer support. The 2017 Side by Side Evaluation (Billsborough et al 2017) found that across online, one to one and face to face group support, a larger number of people chose not to engage further when they felt they no longer had a specific need to, because of improvements in general health/ well-being or because

they were able to access more support from friends and family. A small number of individuals also reported that they withdrew from both face to face and online peer support when they felt unwell. It is of interest that this report also found that some individuals chose to maintain a core level of peer support in their lives, even after some improvements in well-being and that this was often driven by a desire to maintain social contact. The nuances in these findings again hint at some of the potential different ways in which individuals with experience of mental or emotional distress engage with online, face to face group and one to one support. The complexity of why individuals stop engaging with peer support is further illustrated by Markowitz (2015) in a large-scale survey of 553 individuals with experience of accessing face to face mental health self-help groups. Of those who had decided no longer to engage with face to face peer support, 25% said that they were too ill to attend, 12% said they were now feeling better and a further 12% said they had not found the group useful. However, 10% individuals cited time conflicts and 5% suggested that transport was the reason for non-attendance, suggesting that accessibility considerations can make attending a face to face peer support group complicated for some individuals.

Understanding why and how individuals engage with, and participate in, different forms of peer support is important because it provides an important context to how we interpret the positive outcomes that can potentially be experienced from attending a face to face peer support group, accessing an online forum or maintaining a formal or informal one to one peer support relationship. As I have demonstrated in this section, many questions remain around how individuals engage with different forms of peer support and as such, this is an important gap in knowledge.

3.4 Frameworks of understanding

Attempts to measure or demonstrate the impact of peer support can be clearly situated within two different frameworks of understanding; peer support as a 'treatment' and peer support as a contributor to individual well-being. In this section, I consider the value and contribution of both approaches.

3.4.1 Treatment evaluation approaches and randomised control trials as the 'gold standard'

Those championing treatment – evaluation approaches to peer within mental health support (e.g., Pistrang, Barker and Humphreys 2008) argue that the effectiveness of peer support should be judged on the extent to which it can enable an individual to reduce symptoms of mental illness or a reduction in the use of health services. Such studies often employ validated scales, such as the Hopkins Symptoms Checklist or Centre for Epidemiological Studies Depression Scale (CES-D), and promote the use of randomised control trials or longitudinal studies as the gold standard for research. The rationale for this being that it is only by controlling for variables that it is possible to isolate causality.

However, the short-term nature of the randomised control trial and the artificial set up required are potentially limited in their ability to understand the impact of peer support for participating individuals. Humphreys and Rappaport (1994:217) argue that such controlled studies 'may be neither possible nor desirable as the method of choice by which to understand the phenomena of interest' and Davidson et al (1999:170) suggest that such approaches can miss the 'social consequences of mental illness'. A randomised control trial methodology will also often involve allocating or directing an individual to a peer support intervention. As such, the way in which they come to the peer support environment differs considerably from an individual who has independently sought out support from others with lived experience. This has the potential to have repercussions in terms of the outcomes for participants.

3.4.2 Well-being approaches

Whilst ideas of well-being or living well can be traced back to ancient Greek philosophers, they have gained particular prominence in both wider public health and mental health discourses in recent years (Walker and John 2012). In 1946, the World Health Organisation (WHO) developed a landmark definition of health as not just the absence of illness, but as 'a state of complete physical, mental and social well-being' (WHO 1946). The 2000s saw the idea of well-being gain increasing traction in the UK with the Whitehall Wellbeing Working Group publishing a common

understanding of well-being to inform policy makers in 2006 (Walker and John 2012). This identified well-being as 'a positive physical, social and mental state' requiring not only that the basic needs of the individual are met, but also but 'they feel able to achieve important personal goals and participate in society' (Sustainable Development Unit 2006).

Ideas of well-being can be argued to have further salience for those experiencing mental or emotional distress as a way to re-orientate perspectives and bring an approach that 'starts with people themselves, rather than theories about them' (Fernando 2010:85). Fernando (2010) suggests that ideas of well-being within mental health have emerged because of a dissatisfaction with the way in which bio-medical models have influenced both how mental health is understood and the delivery of mental health services, imposing ideas of health and illness. Loat (2011:52) also explores bio-medical and psychotherapeutic models of mental health, arguing that bio-medical models also separate an individual's difficulties with their relationships and the environment around them.

This is considered by Collins (2019), who traces the different approaches taken to defining high level outcomes in mental health services, the emergence of clinical scales such as the PHQ-9 and the GAD – 7 in the mid-1990s, and their current use in the NHS both as diagnostic tools and tools to measure conditions over time. This evaluation recognises that such measures isolate symptoms of disease from the wider social issues impacting on an individual's life and can serve to discount individual understanding of their experience of mental distress. Collins (2019) also recounts how the recovery movement, which also emerged in the 1990s sought to address underlying causes, rather than medical symptoms of mental distress.

Well-being is based on the standards or values that people themselves seek and their subjective realities or judgements of their lives. Burns–Lynch, Brusilovskiy and Salzer (2016: 47) suggest that the well-being of an individual is 'intricately linked' with their recovery from mental or emotional distress as it describes how they appraise their life and their levels of life satisfaction. Recovery within mental health is increasingly being conceptualised and understood not as the absence of disease, but as an ongoing process of learning to live with your condition, and of rebuilding a sense of purpose, agency and meaning (Davidson et

al 1999). Therefore, the unique and personal nature of mental or emotional distress necessitates pathways to well-being that go beyond the established frameworks (Collins 2019). Collins reflects that:

‘The broader frameworks to support recovery consider other requirements needed to improve wellbeing – for example, employment and housing. Yet people struggling with mental health problems appear to care about a broader range of outcomes still. In moments of crisis, they turn to services not just for a diagnosis or for medical care, or support in developing resources and capabilities, but for sanctuary, to alleviate suffering, to help make sense of what has happened, to grieve, to recover voice, to rekindle hope, to address the stigma that comes with a mental health diagnosis, and perhaps many other important things besides’ (2019:28).

3.5 Processes and outcomes from engaging with different forms of peer support

A number of studies apply these two different frameworks to explore the positive or negative outcomes resulting from engagement with different forms of peer support. Depending on the approach taken, some studies also seek to measure or explore the processes that are taking place in peer support environments and that ultimately contribute to positive outcomes. It is not practical to address every single benefit or limitation associated with each different form of peer support. As such, I have chosen to focus on the most prominent areas in which, from my appraisal of the literature, I feel peer support can have impact. Firstly, I explore what is known about how different forms of peer support contribute to the outcomes of symptom reduction. Many of the articles in this section demonstrate how research in this field often focuses on either processes or outcomes in isolation, rather than a connection between both (Markowitz 2015 offers a useful critique of this and response). I then go on to look at to consider studies that focus on different contributors to well-being. Firstly, to what extent different forms are seen to offer forms of social support. In doing so, I refer to the theories of Cobb (1976) and Cassel (1976), both identified by Salzer (2002) as important theoretical perspectives from which it is possible to understand the benefits of peer support. I then consider how drawing on experiential knowledge (Borkman 1976) and helper therapy (Riessman 1965, Skovolt 1974) can

lead to positive outcomes for individuals, and whether these differ across different forms of peer support. Finally, I outline research which has sought to understand potential challenge of peer support to well-being; namely the ways in which engagement can lead to experiences of conflict or distress.

3.5.1 Symptom Reduction Studies

Several studies have undertaken meta-reviews or systematic reviews in order to understand how peer support might reduce the symptoms of mental illness. Although the body of research is smaller than the research that explores well-being, arguably because of the methodology adopted – primarily RCT's - these type of studies have had more influence on policy and practice in the UK in recent years. In 2008, Pistrang, Barker and Humphreys examined 12 studies (11 of which looked at group support and one study of online support), which assessed psychological symptoms, rates of hospitalization, adherence to psychiatric medication or social functioning. They find that seven of the 12 studies reported some positive changes in mental health for group members. In 2014, Lloyd Evans et al conducted a systematic review and meta-analysis of randomised control trials for peer support, specifically for individuals with severe mental illness. This involved a review of 18 different randomised control trials, with 5597 participations; 4 mutual support groups, 11 peer support services and 3 peer delivered services, which had taken place in America, Canada, Australia and the UK. The findings of these studies are pooled under three categories: mutual support, peer support and peer delivered services, to allow for the considerable difference between a peer delivered service and mutual support. Lloyd Evans et al. conclude that from the quality of research undertaken to date, 'there is little or no evidence that peer support was associated with positive effects on hospitalisation, overall symptoms or satisfaction with services' (2014: 1). It is clearly apparent from these two studies alone, the numerous difficulties that emerge when trying to assess the impact of different forms of peer support with potentially very distinct forms of delivery, even more so when delivered in numerous country settings. Additionally, the use of validated scales also makes numerous assumptions around what can be perceived to be 'a successful outcome'. As one example, attending a peer support group could in fact empower an individual to question the health services they receive, potentially

ultimately to their benefit, but from a treatment evaluation perspective, this would not be taken to be 'a positive effect'.

Since the emergence of online peer support in the late 1990s, a literature base has also started to develop which specifically examines the potential of online groups to alleviate symptoms of mental health. Houston, Cooper and Ford (2002) and Breuer and Barker (2015) both find evidence that those who actively used online support did experience a reduction in their depressive symptoms. Houston, Cooper and Ford (2002) recruited and then measured the outcomes of 103 individuals using an internet support group over a one-year period. Participant outcomes were recorded primarily using the Centre for Epidemiologic Studies Depression Scales (CES-D Scale). Participants also completed the Medical Outcomes Study Social Support Survey to measure changes in social support and which asks Likert style questions which plot frequency against statements such as having someone to listen to you or to give you advice. Breuer and Barker (2015) offered 15 NHS patients access to an online peer support group for 10 weeks. A number of pre-post measures were used, including the CORE—Outcome Measure to measure psychological distress, the PHQ-9 and Depression Self-Stigma Scale as well as the Medical Outcomes Study Social Support Survey. Both studies found that social support (as defined by Medical Outcomes Survey) did not increase with access to online peer support, however, with the limited time period in which the Breuer and Barker study was conducted, it is possible to question whether sufficient time was given for the development of new social support relationships. It is also worth noting that in both these studies participants were recruited specifically for a study rather than actively seeking out peer support themselves.

In their 2004 systematic review of online peer to peer interactions, Eysenbach et al find only 6 studies that examine pure 'peer to peer' online interactions and one with a specific peer to peer arm that could be evaluated. In the remaining 31 studies that meet their inclusion criteria, online peer support is delivered alongside other health interventions, demonstrating the difficulty with which it can be possible to effectively isolate the impact of peer support in treatment evaluation studies. Of the 6 peer to peer interventions, none are randomised control trials, and all but one have some involvement from a professional, providing moderation for example. It is also important to note that Eysenbach et al examine peer support across a number of

health conditions (weight loss, smoking cessation and diabetes), and that only 12 of the studies that meet their inclusion criteria measure for depression and social support, 3 of which find significant improvement in depression scores. They conclude that:

‘given the abundance of unmoderated peer to peer groups on the internet, research is required to evaluate under which conditions and for whom electronic support groups are effective and how effectiveness in delivering social support electronically can be maximised’ (Eysenbach et al 2004:328).

From the studies above, there is an indication that from a treatment evaluation perspective, engaging with online peer support will not lead to a reduction in the symptoms associated with experiences of mental or emotional distress. However, as Melling and Houguet-Pincham (2011) helpfully observe, this may not be the most appropriate framework through which to measure outcomes from engaging with peer support:

‘Peer support services, both face to face and those provided online, generally act as an adjunctive component of an individuals’ mental health management. The primary aim of online peer support services therefore is to provide support, compassion, and understanding to facilitate therapeutic changes such as improved self-esteem, self-efficacy and coping strategies. Accordingly, the efficacy of online peer support services would be more accurately ascertained by measuring outcomes in therapeutic changes as opposed to clinical outcomes in symptom reduction.’

Melling and Houguet-Pincham provide a direct critique of both Houston, Cooper and Ford (2002) and Eysenbach et al (2004), specifically identifying that in the former study, peer support was used alongside clinical support for depression and that no control group was in place. Reflecting on Eysenbach et al, they argue that research needs to go beyond simply clinical and social support outcomes to consider therapeutic outcomes such as empowerment, self-esteem and coping skills.

Studies of peer support and symptom reduction seek to isolate peer support from other interventions or life circumstances, and test its efficacy using validated scales,

often designed for measuring clinical interventions. However, in this section I have demonstrated the many difficulties in measuring peer support in this way, including short time scales, and the inclusion of many different forms of peer support in one analysis, regardless of different levels of professional intervention and form of delivery. Most importantly, whilst there is merit in measuring clinical outcomes in this way, focusing solely on symptom reduction ignores the psycho-social potential of peer support. It is to the latter that I now turn.

3.5.2 Well-being studies

Social support

Cobb and Cassel both published seminal works in 1976 which stress the impact of social support on our mental and physical well-being. Cobb (1976) examines how believing you are cared for and loved, esteemed, or a member of mutual obligation can lead to improved outcomes in a number of stressful life situations. Cassel (1976), in his exploration of the social environment to host resistance, reviews a number of studies that suggest that those with more social resources have better physical health outcomes.

Individuals experiencing mental or emotional distress are suggested to be more at risk of social isolation than members of the general population (Social Exclusion Unit 2004). In their 2016 study, Lasgaard, Friis and Shevlin, explore groups at high risk of loneliness across the lifespan in a Danish context, finding an association between individuals with a prolonged mental disorder and severe loneliness. This isolation can be categorised into two types: social isolation, whereby an individual lacks social contact itself, and emotional isolation, where an individual has a support network but feels emotionally disconnected from those around them (Weiss 1973). Peer support arguably provides a response to both types of isolation; by providing both a way to meet and make contact with new individuals, and by potentially connecting individuals with others who can offer more genuine understanding because they have direct experience of mental or emotional distress themselves (Mead and MacNeil, 2006).

Studies that examine the relationship between peer support and social-emotional support tend to sit within a well-being framework because they move beyond

symptom management to consider how well an individual can live beyond their experiences of mental or emotional distress. Oades, Deane and Crowe (2017:99) offer the concise summation that 'Traditional mental health care emphasises living with fewer symptoms; mental health recovery may be seen as living well with illness and wellbeing as simply living well'. Social support may enable individuals to better manage their symptoms, but more importantly, it is essential for individuals to, in a broader sense, live the lives they want to lead and achieve their own personal goals.

Several studies have indicated that peer support, delivered in a face to face group setting, builds social support and that this may be a significant contributor to improvements in individual well-being. Behler et al. (2017) conducted 20 interviews with individuals attending community-based bi-polar depression and peer support groups in the U.S. As their interviews were based on principles of narrative inquiry, participants were able to tell the story of their involvement in their own words. Analysis of the interviews, alongside group observation identified the way in which group members were able to relate to participant experiences in a more direct way than family or friends. The study also found that the relationships built in the group extended outside of meetings, and that participants met both on a one to one basis (as friends) and in groups, for example holding a pot luck supper, concluding that in this way attending peer support groups can provide an experience of community. The 2017 Side by Side Evaluation of peer support projects in the UK produced similar findings. Interviews with participants highlighted that connections developed within a group setting often extended into friendships outside of the meetings and log data suggested that individuals increased levels of supportive contact as they shared more in face to face peer support group settings (Billsborough et al 2017).

Some academics have argued that individuals are able to access equivalent or even greater levels of socio-emotional support in an online peer support setting. King and Moreggi (2006) propose that participants in online group experience a form of emotional support with different interpersonal dynamics than they would experience in their traditional support networks. Anonymity and a lack of visual markers which might lead individuals to consider themselves different to others in a face to face setting (e.g., differences in age, ethnic group membership and gender) arguably

creates a greater sense of ease and reduces inhibition (King and Moreggi 2006). Donn and Sherman (2002) contend that this allows for a more profound connection, with individuals feeling more able to self-disclose their experiences than would be possible in a face to face setting. There is a suggestion that connecting online is more comfortable for some by the work of Schrank et al (2010) who conducted 26 semi-structured interviews with individuals with clinical diagnoses of depression. From the interviews, it was found that 14 participants had used chat rooms or networking sites and 5 participants had exchanged information about illness with peers online. Across a number of participants, there was a recognition of the importance of not being confronted with social anxieties when engaging with peers online.

Several studies employ a content analysis approach to better understand the content of online peer support forums and the extent to which they represent an exchange of socio-emotional support. Finn (1999) reviews 718 messages from one online forum, finding the majority of discussion (55.3 percent) was related to socio-emotional support and Griffith (2015) in an analysis of 586 posts on a mental health message board finds that of 453 positive messages, 65.3% related to valued social interactions and support. The findings of both studies suggest that socio-emotional support is a strong feature of online peer support, notwithstanding the fact that measuring the content of forums rather than the impact on participants of their engagement only allows us a very limited understanding of how offers of socio-emotional support were received by participants and how these contributed to overall individual well-being.

However, as previously touched upon in the symptom reduction section of this chapter, several studies also indicate that the participation in an online peer support group does not lead to increased levels of socio-emotional support for individuals experiencing emotional or mental distress. Houston, Cooper and Ford (2002) and Breuer and Barker (2015) both explore the impact of online peer support on levels of social support (with the employment of validated scales) and find that this did not increase for participants accessing online peer support. This could potentially be explained in part by the frequent turn over in membership of online groups (Galston 2000), meaning that the nature of relationships formed online is often short-lived, or the short-term nature of the research period studied. However, it has

also been questioned whether it is possible to achieve the same type of social connectedness on and off line. In an effort to throw light on this and to understand whether social connectedness is equivalent on and off-line, Grieve et al (2013) ask 344 participants from an Australian University to complete a survey of measures of online and off-line social connectedness. Their analysis finds that social connectedness derived from Facebook is distinct from but related to social connectedness derived from face to face. In a second stage to the study, it was found that Facebook social connectedness had a moderate, positive relationship with subjective well-being; as well as lower levels of depression and anxiety, leading the authors to conclude that social connection on Facebook offers a separate social medium through which it is possible to build and maintain relationships.

Some researchers go further and suggest that accessing online peer support could in fact also have a detrimental impact and lead to a decline in communication with your wider social network. After conducting an online survey with 158 members of health-related online support groups, Chung (2013) concurs with Helgeson's earlier findings that accessing online support can be detrimental to pre-existing support relationships (Helgeson et al 1999) and can reduce satisfaction with the emotional support they receive from these relationships (Helgeson et al 2000). However, Chung (2013) also argues that online support can become an alternative form of support for those who lack satisfactory support from offline social contacts.

Kim, LaRose and Peng (2009) survey 635 undergraduate students, based at two mid-western universities in the U.S. using several validated scales to measure loneliness (Russell's UCLA Loneliness scale), social skills (Self-Monitoring scale) and preferences for online social interaction against internet use. Their analysis also finds that rather than relieving psychosocial problems, internet use could in fact lead individuals who were lonely or without social skills to develop compulsive internet behaviours which ultimately resulted in negative life outcomes and harmed significant offline relationships. However, it is also important to note the limited demographic included in this study and the unique nature of the undergraduate experience.

Whilst there is some consensus that attending a face to face peer support group is a source of social support, there is less agreement when it comes to the literature on

online peer support. This may partly be attributed to the varied disciplines, approaches and parameters of different studies but also suggests the considerable complexity around how different forms of peer support can serve to increase social contact and/or reduce emotional isolation; an area in which there remains considerable scope for further research.

Self-esteem

In his theory of 'Helper Therapy' Riessman (1965) argues that by giving support to others, individuals are able to develop a sense of competence by having a positive impact on another's life and social approval from both those they help and others. Skovholt (1974) further suggests the effective helper can feel an increased sense of interpersonal competence and sense of equality whilst also receiving social approval and valuable personalized learning. Mutuality, reciprocity or 'two-way interactions' feature across numerous definitions of peer support (e.g. Mead 2003, Solomon 2004). Reciprocity is both seen as a key determiner of difference between professional health services and peer support (Munn-Giddings and Borkman 2018), with reciprocal helping as an important contributor to the potential positive outcomes individuals can experience from engaging with peer support (Salzer 2002).

Munn-Giddings and Borkman (2018) explore reciprocal processes in a face to face peer support setting in detail. Within the group itself, the use of a 'sharing circle' is a way for listening and sharing personal experiences. This provides 'ongoing and continuing opportunities for its members, not only to receive help but also to help others and thus keep the helper/helpee relationship in balance' (Munn-Giddings and Borkman 2018:66). Reciprocity extends to include the organisation and leadership of the meeting itself and, in some examples, the network of supportive relationships that develop around face to face peer support groups (such as sponsors or buddies). Munn-Giddings and Borkman argue that the reciprocal processes support shifts in how individuals understand their experiences, reduced stigma and empowerment, by both inviting and valuing personal contributions.

The balance between giving and receiving in naturally occurring (face to face) peer support groups for individuals experiencing mental or emotional distress is considered by Bracke, Christiaens, and Verhaeghe (2008). Completing structured

questionnaires with 628 individuals accessing peer support groups, the study is able to conclude that self-esteem is influenced by the total amount of perceived peer support that an individual gives and receives and that a balance between these improves feelings of self-worth. The authors note the feelings of dependence and powerlessness that can emerge as a result of being a recipient of support without being able to reciprocate.

In their recent Side by Side Evaluation, Billsborough et al (2017:4) found that the 'most change was achieved' for individuals when there was 'active giving and sharing of peer support in a two-way interaction'. Several interesting differences were found in interviews that explored experiences of giving and receiving support in different peer support environments. In face to face peer support groups, numerous benefits were mentioned from giving peer support. In one to one peer support relationships (formal, community-based), understandings of reciprocal giving still applied but 'giver' and 'receiver' roles were more demarked. When it came to online peer support, some interviewees talked about 'giving something back' in the same way they did as in face to face peer support groups, but the benefits of giving were not as significant as in a face to face context. Some comments also suggested that two-way interactions differed in an online environment, with some people being more active in giving, and others more active in receiving (rather than both giving and receiving support).

Chung (2013) and Takahashi (2000) suggest that support may be less reciprocal online because of the number of participants. Support relies less on one to one exchange, and is more generalised, as such there is less expectation on participants to reciprocate to others. These findings offer one initial insight into the differences in reciprocal relationships between different forms of peer support and the impact this has on the outcomes individuals derive from peer support is an area that merits further investigation.

Both in face to face groups and in online peer support environments, improvements in self-esteem and access to new sources of experiential knowledge have been identified as contributing to individuals feeling a greater sense of control over their personal situation and lives. Seebomh et al (2013) analyse data from 21 interviews with face to face peer group coordinators and 20 group discussions against The

National Mental Health Development Unit (2011) Mental Well-being Checklist in order to examine the contribution of face to face peer support groups to mental well-being. As mental well-being was not the initial area of research focus, the reflections shared by group members on this topic arose organically without prompts. The study finds that face to face peer support groups made a strong contribution to members' mental well-being by building self-esteem, confidence and new knowledge, which in turn increased feelings of self-efficacy and the sense of control that individuals felt they had over their situation. These findings are also reflected in the 2017 Side by Side Evaluation where participants describe how attending face to face peer support groups enabled them first to build confidence and skill in making use of peer support, before transferring this new skill set to other areas of their lives (Billsborough et al 2017). From their analysis of 32 participants of online peer support groups for breast cancer, arthritis and fibromyalgia, van Uden-Kraan et al (2008) identify that processes such as helping others, exchanging information and finding recognition, lead to numerous positive outcomes, including 'being better informed; feeling confident in the relationship with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism and control; enhanced self-esteem and social well-being; and collective action'(2008:56).

Finally I turn to an area that is often omitted in the peer support literature – the potential for peer support to cause distress itself. There is very little literature in this area and that which exists does not fit neatly into either a symptom reduction or well-being framework as such but arguably has important implications for individual well-being.

Misunderstandings, conflict and distress

A particular concern that has emerged around online peer support is the potential for it to cause distress to participants. This is seen to be a specific issue for online support because of the non-verbal and open way in which people interact online (King and Moreggi 2006) with some academics asking whether the potential for 'adverse events' is greater online (e.g. Easton et al 2017). Kaplan et al's 2011 study appears to offer confirmation of such concerns. The authors conduct a randomised control trial with 300 participants 'with psychiatric disabilities' using either a Listserv,

Bulletin board or control group and examine patterns of distress against participation, finding overall that participation in unstructured online forums did not enhance the well-being of participants and that increased participation could lead to increased distress.

Conversely, two further studies suggest that relatively small numbers of participants may be experiencing distress whilst engaging with online peer support. Easton et al (2017) conducted four online surveys with participants in online peer support platforms. Analysis of the responses found that only 8.37% of participants reported negative experiences online. Of those, a dominant theme was negative moderation rather than distress caused by fellow participants, although the authors do note that reading user posts was a cause of distress or worry for some. Griffiths et al (2015) analyse 586 posts on an online message board, to find that 453 (77.3%) reported advantages and 133 (22.7%) reported disadvantages. These disadvantages were identified as negative personal change perceived disadvantages of board rules/moderation, unhelpful social interactions/contact with other members and technical obstacles to using the board.

Two studies also identify that experiences of conflict or distress are not unique to an online setting. In face to face groups, that are dealing with highly stigmatised areas, such as self-harm and schizophrenia, there is some indication that attending a group may be a source of distress for some people. In their 2003 user-led research on the experience of attending self-help groups, Clarke and Smith undertook 12 in-depth interviews and 34 questionnaires in which almost half of participants described feeling worrying about others in the group and how this was a source of distress for them. One participant also described struggles to fit in with a face to face group and a further participant said she had experienced difficulties in connecting and finding acceptance from other group members. Longden, Read and Dillon (2017) devised a customised questionnaire that was completed by 101 participants in Hearing Voices Network groups. Nearly 35% of participants reported finding it distressing attending face to face peer support groups, because of the need to discuss painful issues. However, it is of interest that experiencing this form of distress did not necessarily mean that group members would not also experience benefits:

‘Our results show that individuals with a diagnosis of psychosis/schizophrenia who have heard voices for many years can derive various benefits from attending HVN groups. Given that around a third of participants (34.6%) reported finding the group distressing at times, these gains still appear attainable despite the inherent difficulties in discussing the painful issues that are often related to hearing voices. Indeed, for some group members it may have been partly because there was a chance to talk about distressing material, without being judged or pathologized, that was beneficial’ (2017:184).

Studies of distress from participation both in online and face to face group peer support illustrate the complexity of the way individuals experience different forms of peer support and the importance of avoiding assumptions. Whilst research to date provides useful indicators, relatively little is known about experiences of distress across different forms of peer support and as such this is an important area for research.

3.6 Rationale for this study

The idea for a study that introduced a pluralistic approach to peer support first emerged following indications from the national ESTEEM project that individuals use different forms of peer support concurrently (Boyce et al 2014). This formed the basis of a Vice Chancellor Studentship which I commenced in 2018.

In my subsequent engagement with the literature, I have found that whilst increasing attention has been paid in recent years into the impact of peer support, such research has a tendency to focus on formal or intentional forms of peer support. This is reflected in Mind’s 2013 report, which states that:

‘Much of the research into peer support has primarily, but not exclusively, explored intentional peer support or peer working which more often take place within one to one relationships’ (Faulkner et al 2013:6).

Academics themselves have also observed the lack of interest in evaluating ‘unsophisticated’ online peer to peer interventions as opposed to interventions led

by health professionals (Eysenbach et al 2004:328), with others stressing the importance of 'valuing peer support in all its variety' (Faulkner and Kalathil 2012:8).

Faulker and Kalathil (2012) specifically call for more investment into community-based peer support initiatives so that equal attention is given to how diverse peer support groups and activities contribute to the well-being of people with experience of mental or emotional distress. Representatives from the charity sector, such as Mind (Faulkner et al 2013:9) also caution against allowing the growth of formal or intentional peer support 'to overshadow the many ways in which mutual help, self-help and peer support continue to retain their meaning for people and communities within mental health'.

Through undertaking this review it has become evident that forms of peer support in the UK have very different levels of visibility and that not all forms of peer support have received the same level attention in UK policy or indeed the academic literature. As individuals value different forms of peer support in their recovery journeys (Onken et al 2002, Billsborough et al 2017), further exploration of community-based forms of peer support is essential to ensure that individuals experiencing mental or emotional distress can access the form of peer support they need, when they need it. In essence, a rebalancing is needed.

It is also important to reflect on the research agendas and value systems promoting treatment evaluation perspectives and randomised control trials as a gold standard in the study of peer support. Concern has started to emerge that, in a context of austerity, peer support has started to be viewed as a 'cost effective alternative' to clinical services (Falkner and Basset 2012). Studies that focus on cost-efficacy hold the potential to undermine the value of offering peer support as a complementary addition to clinical services or other psycho-social interventions, as a unique phenomenon. Focusing on the ability of peer support to reduce use of health services and save money arguably only offers a very narrow understanding of the impact of peer support for individuals, especially when it is offered on a restricted basis and/or offered as part of an overall treatment package. Barak, Boniel-Nissim, and Suler (2008:1878) argue that an important distinction must be drawn between peer support and other therapeutic interventions. Whilst therapeutic treatments might be expected to cause 'durable changes relevant to a problem

question', peer support cannot be 'expected to produce such outcomes but, rather, to contribute to participants' general well-being'.

The field of peer support is complex and no one framework can capture all the potential ways in which different forms of peer support can contribute to individual well-being. However, for myself, a well-being framework offers the opportunity to understand the potential benefits or limitations of peer support from the perspective of the individual and how participation in different forms of peer support can enable a sense of thriving rather than just surviving in their world. Treatment evaluation perspectives rarely allow for the complexity of processes that might lead to an individual feeling less depressed or anxious as a result of accessing an online peer support group, attending a face to face peer support group or engaging one to one with a peer. Whilst not perfect, well-being perspectives do not reduce individuals with experiences of mental or emotional distress to the sum of their symptoms, but rather allow for a more holistic interpretation of the individual and what they have to offer.

Studies of peer support from a well-being perspective do exist, however they tend to concentrate on one type of peer support only (e.g., Seebohm et al 2013). This is aptly demonstrated by the extensive review of over 1000 peer support studies in 2015 which concluded that it 'not possible to suggest that one mode of delivery is any more effective than others' (Nesta/ National Voices 2015:17) because of the lack of studies that look across different forms of peer support.

Findings from the national ESTEEM project (Boyce et al 2014) and more recently, the 2017 Side by Side Evaluation (Billsborough et al 2017), have started to draw attention to the unique contributions offered by different forms of peer support. They suggest that a plurality of use exists, whereby individuals actively choose to access more than one form of peer support concurrently or at different stages to improve their mental well-being. Indeed, they stress the importance of ensuring diverse provision to provide individuals with choice about the form of peer support they choose to engage with. This has led academics such as Borkman and Munn-Giddings (2020) to stress the importance of looking at how individuals use different forms of peer support in combination and the considerable scope for research in this area. I argue it is important to revisit the landscape of peer support to develop a

better understanding of the motivations and experience driving this plurality of use, to understand the field, and inform relevant practice in mental health.

3.7 Chapter Summary

In this chapter I have examined current understanding on how different forms of peer support contribute to the well-being of individuals with experience of mental or emotional distress. In doing so, I have identified two clear frameworks that are applied in the literature to evaluate the impact of peer support. I argue that the first of these, treatment evaluation perspectives, only examine clinical outcomes and as such, do not fully acknowledge the therapeutic value of peer support. Methodologies such as randomised control trials, although often promoted as a 'gold standard' for research, can be considered partial or even inappropriate for evaluating peer support as they create artificial conditions which do not replicate real-life experiences. As such, a well-being perspective is judged to be the most appropriate framework to explore both the therapeutic processes and outcomes taking place in peer support environments and how these contribute to individual well-being.

I have presented the rationale for this study, arguing for a rebalancing of the policy and research agenda, to give the same prominence to community-based peer support as more formalised or intentional forms of peer support. I call specifically for the need for a pluralistic approach to look across different forms of peer support (one to one, face to face, online), to consider how they are used in sequence or combination, and to better understand their unique contribution to well-being.

Chapter Four

Methodology

4.1 Introduction

The review of the literature led to the emergence of a research question that asks:

‘How do people who have experienced mental or emotional distress use different forms of community-based peer support to enhance their well-being?’

It also identified several areas which merited investigation within this overarching question:

- Motivations of individuals for accessing different forms of peer support
- Pathways between different forms of peer support
- Types of participation and patterns of use
- Barriers to accessing different forms of peer support
- Individual perceptions of how different forms of peer support enable participants to enhance their well-being

In this chapter, I situate the research in an interpretivist research paradigm and provide a rationale for the use of an abductive research strategy and qualitative methodology to explore how people use online, one to one or group peer support in combination to enhance their well-being. I then outline the specifics of the research design, including the approach taken to sampling, data collection and data analysis and concludes with a consideration of the strategies employed to ensure trustworthiness of findings and my positionality as a researcher.

4.2 Paradigm of inquiry

How we understand the world influences how we investigate it and the theories we construct (Fleetwood 2005). Both the methods and methodology we employ reflect assumptions of the reality we understand to underpin our work (Crotty 1998) and therefore it is necessary to consider the paradigm of inquiry underlying this research.

Paradigms of inquiry have perhaps been most famously conceptualised by Kuhn (1970) as a constellation of beliefs, shared by a scientific community (Crotty 1998). This constellation or cluster of beliefs influences all aspects of research, from defining the subject of study, to the interpretation of results (Bryman 1988).

Positivism or the scientific method can be argued to have dominated social research in the western world since the publication of Comte's *Course of Positive Philosophy* in the early 19th Century (Moses and Knutsen 2007). Comte's work proposed continuity between the study of the natural and social world, with the employment of empiricism observation. Movements such as Logical Positivism that emerged in Vienna in the 1920s reinforced ideas of observation, stressing the need of verification from direct experience, and dismissing any understanding of a concept or proposition which could not be verified by experience as 'meaningless' (Crotty 1998:25). Finally, a view emerged in the post-war period that all science should be concerned with developing general or universal laws to explain phenomena (Crotty 1998).

Positivism takes an ontological position that views reality as a series of discrete events which can be directly observed. As such, it argues that similar methodologies can be applied to explore both the natural and social world. However, a number of academics (e.g. Collingwood 1962, Popper 2002) have questioned whether the same methodologies can be employed in this way:

'For many observers, the natural and social worlds are inherently different, and this difference is obvious: people, unlike particles, think. The subjects of social studies are self-aware, reflexive, creative and intentional: they rationalize their actions; they are motivated by purpose; and they enjoy a certain freedom of action. All of these inherently human capacities make it possible to doubt whether mechanistic assumptions about natural patterns in the real world make sense when studying the social world' (Moses and Knutsen 2007:146).

This has led to the emergence of an alternative understanding of the nature of reality and knowledge in the form of interpretivism.

4.2.1 Interpretivism

The roots of interpretivism are often attributed to the works of Weber who argued that explorations of social phenomena should be based on the 'interpretive understanding' (1964:88) of social actors, rather than the direct observation of the social researcher. Weber's often quoted *verstehen* stresses understanding rather than the explaining phenomena (Crotty 1998:67) and is influenced by the work of such academics as Schütz (1963), who argued that natural and social reality are different and therefore require different modes of inquiry. Schütz stresses the meaning that the social world holds for the social actors within it and how their preselection and preinterpretation of the social world determines their behaviour and 'the goal of their action' (1963: 305).

Whilst definitions of interpretivism vary, this study employs the following definition from Blaikie (2007:124) which states:

'According to Interpretivism, the study of social phenomena requires an understanding of the social world that people have constructed and that they reproduce through their continuing activities. However, people are constantly involved in interpreting and reinterpreting their world – social situations, other people's actions, their own actions and natural and humanly created objects. They develop meanings for their activities together, and they have ideas about what is relevant for making sense of these activities. In short, social worlds are already interpreted before social scientists arrive'.

Accepting that human action is meaningful and that people act on the basis of the meanings they create, shifts the role of the social researcher from direct observation of phenomena to the interpretation and understanding of the social world from the social actors' perspective. Interpretivism prioritises the subjective interpretations that people hold of social phenomena (Matthews and Ross 2010) and perceives the constructed meanings of social actors as the fountain of knowledge (Lincoln and Guba 2013).

4.2.2 Ontology

Whether subjective interpretations or the constructed meanings of social actors are based on a concrete and external reality was a key ontological consideration for this study. Academic discourses around ontology, or 'the nature of social reality' (Blaikie 2007:13) often adopt a realist position, in which it is argued that the natural and social world exists independently from human action and observation (Blaikie 2007) or a relativist/idealist position, in which reality is perceived to have no independent existence from our thoughts (Blaikie 2007). However, expressing ontological positions as a dichotomy, or as two mutually opposing positions, arguably masks the complexity that exists in conceptualisations of reality in the social sciences (Blaikie 2007). Furthermore, the realist position 'is often taken to imply objectivism' (Crotty 1998:10) which confuses the existence of an external reality with the existence of meaning outside consciousness:

'Accepting a world, and the things in the world, existing independently of our consciousness of them does not simply imply that meanings exist independently of consciousness... The existence of a world without a mind is conceivable. Meaning without a mind is not' (Crotty 1998: 10-11).

The different nuances between 'realist' positions is explored by Blaikie (2007), who introduces additional ontological categories and identifies a key distinction between those who hold a shallow realist position 'what we can observe is what exists' (Blaikie 2007:14), and those who argue for a cautious or subtle realist position, both of which uphold a belief in an external reality. These positions argue that it is not possible to observe an external reality directly, because of imperfections in the human senses (as for the cautious realist - Blaikie 2007:15) or because all knowledge is based on assumptions (as in the subtle realist position - Blaikie 2007:15/16). For myself, reaching an ontological position was difficult because whilst I felt that natural reality did exist, with peer support groups and relationships as real phenomena external to the self, I acknowledged that the way in which individuals interact and create meaning around those peer interactions could have implications for how they viewed their world and their individual reality. Ultimately, I felt that the 'subtle realism' advocated by Hammersley (1992) best represented my position because it recognises the existence of an independent natural reality but

argues that it is not possible to access or observe it directly. Rather, it argues that all access to 'reality' is through subjective human perception. Hammersley (1992:50-51) suggests that the aim of social research is to represent reality but that this representation always reflects a position, or point of view. This perspective renders 'some features of the phenomena represented relevant and others irrelevant' (Hammersley 1992:50-51) and can lead to multiple explanations of phenomena.

4.2.3 Epistemology

In this study, I sought to understand individual experiences of different forms of peer support and how they influence well-being. Therefore the 'knowledge' I wished to access was composed of individual perceptions and accounts of these experiences. I consider such accounts as individual constructions and as such, this study is grounded in an epistemological position of constructivism, which has developed from the wider paradigm of interpretivism. Epistemology can be understood to define 'the nature and scope of human knowledge, with what kinds of knowledge are possible' (Blaikie 2007:4). A key difference is whether knowledge can be seen to already exist and be available for 'discovery' or if knowledge is generated through our engagement with the world. In broad terms, a constructivist position argues that 'meaning is not discovered but constructed' (Crotty 1998:8-9). Constructivism and constructionism have been conceptualised in the literature as research paradigms (e.g. Lincoln, Lynham and Guba 2013, Creswell 2014), ontological positions (e.g. Bryman 2016) and as epistemological positions (e.g. Blaikie 2007 and Crotty 1998). Further confusion can be generated by the fact that the terms constructionism and constructivism or interpretivism and constructivism are sometimes used interchangeably. However, in this study I draw a key distinction between social constructionism, in which the world is understood through 'social artefacts, products of historically situated interchanges between people' (Gergen 1985:267) and constructivism, which proposes that 'each individual mentally constructs the world of experience' (Gergen 1999:237). Gergen describes the fundamental difference between these two approaches:

‘For constructivists the process of world construction is psychological; it takes place “in the head”. In contrast, for social constructionists what we take to be real is an outcome of social relationships” (Gergen 1999:237).

Having established the ontological position as subtle realism and an epistemological perspective of constructivism, consideration now turns to how my research strategy sought to access individual constructions of their experiences of peer support.

4.2.4 Research strategy

The focus for this study was on the meaning that citizens attribute to their experiences of peer support, and how this in turn influences their well-being. Scholars often identify two key strategies of inquiry – deductive, in which research is conducted against existing theory, and inductive, in which theory is allowed to emerge from the data. However, Bryman (2016) and Blaikie (2007) propose a further research strategy in the form of ‘abductive’ inquiry.

Abductive research is argued to involve

‘Constructing theories that are derived from social actors’ language, meaning and accounts in the context of everyday activities. Such research begins by describing these activities and meanings, and then derives from them categories and concepts that can form the basis of an understanding or an explanation of the problem at hand’ (Blaikie 2007:90).

Whilst this is similar to an inductive logic in that it allows theory to emerge from the data, abductive inquiry requires the researcher to both ground themselves in the perspective of social actors, and come to a social scientific account of the social world from the perspective of participants (Bryman 2016: 394). The researcher must remain close to the world view of the participants, expressed in their voices (Bryman 2016:394). This is of particular relevance to a study such as this, which is seeking to explore the meaning that citizens attribute to their experiences of peer support, and how this in turn influences their well-being.

4.2.5 Limitations of interpretivism

Blaikie (2007) summarises the arguments of a number of scholars who have drawn attention to the potential limitations of interpretivism. Firstly, questions have been raised over a reliance on the intentionality of social actors, with Giddens (1984) querying whether it is misleading to suggest that all actions are undertaken with awareness of intention. Fay (1975) also argues that the focus on intended consequences limits the applicability of interpretivism as it cannot explain unintended consequences of actions. Both authors also assert that interpretivism ignores the backdrop of institutions and power structures against which individual social action and intention take place. In doing so, it does not identify sources of conflict and potential areas of social change (Fay 1975). Finally, if the aim of interpretivist inquiry is to understand individual interpretations and experience, a question exists as to how to translate these into findings to inform social policy. Silverman (2014:171) suggests that despite the 'questionable assumptions' of quantitative methodologies, their ability to assess correlations between variables provides clearer direction for policy. Conversely, interpretivist inquiry has the potential to be endless, continually capturing new or different constructions of reality.

Despite the challenges posed by interpretivism, I judged this to be the most appropriate paradigm through which to explore my research question. This study sought to develop understanding of individual experiences of different forms of peer support and how these contributed to their well-being. In order to understand the nuances in their experiences and to explore these as directly as possible, it was necessary to avoid the pre-determined parameters which would have been necessary for a positivist paradigm of inquiry, for example defining peer support as a treatment for a mental disorder. Using an interpretivist paradigm allowed me to get closer to the individual experience and created the space to allow individuals to bring their own meaning to their experiences of peer support.

Furthermore, whilst acknowledging injustices suffered by some individuals in the UK experiencing mental distress, my research did not directly seek to identify potential areas of social change. Finally, whilst policy is often based on quantitative research, I would suggest that this often starts with an assumption about why

people choose to use peer support (relief of depressive symptoms for example). As our understanding of why individuals choose to use different forms of peer support is not extensive, I would argue that this perspective needs to be explored as an initial inquiry into the pluralism of peer support before such assumptions can be explored on a larger scale.

This section has identified interpretivism as the research paradigm of inquiry and the use of an abductive research strategy which takes the direct experience of participants as the fountain of knowledge. The following section outlines how a methodology was identified and undertaken that would successfully generate insights in line with this paradigm of inquiry and research strategy.

4.3 Qualitative Methodology

A basic distinction often drawn between quantitative and qualitative methodologies is that the former focuses on the use of numbers as data and the latter on words. However, as Bryman (2016) notes, there are a number of key further distinctions that go much further than the absence of numbers. Qualitative research has emerged as a way to understand process and meaning above cause and effect (Braun and Clarke 2013). It can be argued to offer more flexibility than quantitative approaches, where a number of decisions are taken by the researcher to facilitate structured data collection (Bryman 2016). In doing so, it allows the focus of research to lie on the participant's framing of a situation or experience, rather than the pre-framing of the researcher, potentially offering us the opportunity to find new insights we could not have anticipated (Braun and Clarke 2013). Qualitative research often emphasises the importance of context, for example the environment in which data has been collected, and how this can be seen to have influenced the research findings (Bryman 2016).

Whilst quantitative methodologies usually employ a deductive approach to generating theory, qualitative methods tend to allow theory to emerge from the collection and analysis of data (Bryman 2016). This allows for new understandings of concepts to emerge that would be pre-determined in quantitative research. Blumer (1954) contends that the use of definitive concepts can restrict and side-line the nuances that can emerge in the data.

Qualitative research also differs to quantitative research in the way it considers the researcher as a key instrument in the research, rather than as a neutral figure. Qualitative researchers reflect on how past historical, social and cultural experiences can shape the interpretations made in a study, and reject the idea of an objective, unbiased scientist. Blaikie (2007:210) suggests that Weber's idea of *verstehen* requires the researcher to place themselves in the shoes of a social actor to truly understand how they perceive the world. Divisions between the researcher and researched potentially become more blurred within qualitative research, with the former becoming more immersed in the world of the participant.

Braun and Clarke (2013:4) recognise the value of qualitative research to generate detailed and complex accounts and to recognise the data gathered in context. A qualitative methodology was adopted for this study as it was seen to provide the best means to understand first-hand how individuals experience different forms of peer support and to avoid pre-existing assumptions about how different forms of peer support can contribute to individual well-being. It would also make space for my own values and experience and reflexivity about how these influenced the research process (my positionality as a researcher is explored in more detail later in this chapter).

4.3.1 Qualitative Interviewing

Qualitative research incorporates a wide number of diverse methods including the use of focus groups, observation, creative methods, ethnography, discourse analysis and the analysis of texts. For this study, I decided that semi-structured interviews to be the most appropriate method for data collection because of the opportunity they provide to generate data for how people think, feel and make choices, rather than observational methods which consider how people act (Braun and Clarke 2013). Research interviews, defined by Braun and Clarke as a 'professional conversation' (2013:77) are frequently categorised as structured, semi structured or open ended (Noakes and Wincup 2004:80). Structured interviews are most often employed as part of quantitative studies and aim to ask participants a number of closed questions, allowing for no improvisation and aiming for uniformity across each interview experience. The interviewer is seen to be neutral and training is often deployed to ensure questions are always asked in the same way. The open-

ended interview lies at the other end of the spectrum, where the interviewer introduces a general topic and then employs active listening whilst this is openly explored with the participant.

I considered that semi-structured interviews, using exploratory questioning would be most appropriate. Bryman (2016:201) defines semi structured interviews as:

‘A context in which the interviewer has a series of questions that are in the general form of an interview guide but is able to vary the sequence of questions. The questions are frequently somewhat more general in their frame of reference than the questions typically found in a structured interview schedule. Also, the interviewer usually has some latitude to ask further questions in response to what are seen as significant replies’

Loeske (2012: 90) argues that whilst the semi-structured interview is a time-consuming methodology, they do allow for extended discussion around how individuals feel and think about very complex topics, in a way which is not possible with a series of pre-determined questions. Whilst group interviews/ focus groups might allow for a wider range of experiences, they do not allow the interviewer to delve as deeply into the individual experience (DiCicco-Bloom and Crabtree 2006:315). Qualitative interviewing, when done well, enables ‘better access to interviewees’ views, interpretation of events, understandings, experiences and opinions’ (Bryne 2004:182). As such, they provided the best avenue to access the attitudes and values of individuals towards different forms of peer support, ‘things that cannot necessarily be observed or accommodated in a formal questionnaire’ (Bryne 2004:182). As this study sought to understand the motivations that led individuals to access different forms of peer support and how they felt these experiences of peer support contributed to their individual well-being, qualitative interviews were seen to offer the most direct access to the individual experience of this social phenomena.

The successful qualitative interview can be seen to depend on the rapport developed between the interviewer and interviewee (Fontana and Fey 2000) and the development of trust, which encourages the participant to share the most information possible in their own words (DiCicco-Bloom and Crabtree 2006). Rapley

argues that whilst the interview may be conversational, it cannot be considered 'just a conversation' (2004:26) as the interviewer is constantly engaged in decisions about which topics to follow up and which to close down. As such, the interviewer guides the conversation and arguably maintains control (DiCicco Bloom and Crabtree 2006). However, Miller and Glassner's (2011:156) observation that 'the respondent is far from a repository of experiences ...but a productive source of opinions and feelings' reminds us that both parties are active in their construction of the interview narrative.

In line with an interpretivist approach, I accepted Silverman's (2014) contention that consideration must be given to whether interviews are straightforward reports of reality or local constructions, however I did not accept that conducting interviews required a pure positivist, naturalist or constructionist position. This is because I felt that the interaction between myself and the research participant produced a narrative account of their social world which demonstrated how they had developed meaning of their experiences of peer support, and the relationship they perceived between these interactions and their well-being. As such, it was possible to look at the content of what was said in interviews, with some consideration and reflection of the 'how', without requiring a detailed deconstruction of how the interview had unfolded. I found Gubrium and Holstein's (1995) concept of the 'active interview' a useful guide and the need for researchers to be reflexive in how they both ask questions and prompt further discussion on specific topic. I spent time reflecting on this following each interview, recording thoughts in my research journal.

4.3.2 Critiques of qualitative methodologies

Bryman (2016) notes several generic critiques made of qualitative methodologies, firstly that they are too subjective and dependent on the individual predispositions of the researcher or that findings are almost impossible to replicate, given the unique and natural circumstances in which qualitative research takes place (as opposed to the controlled settings employed by quantitative studies). Questions have also been raised as to the lack of transparency that can exist, with no clear information given on how sampling or data analysis has been carried out and about the inability to generalize the findings from qualitative studies to the wider population (Bryman 2016). Caelli, Ray and Mill (2003) argue that to establish credibility, qualitative

research must clearly address several of these areas by establishing the theoretical position of the researcher, ensuring congruence between methodology and methods and the analytic lens through which the data has been examined. A number of steps were taken to ensure credibility in this study, and these are discussed in detail later in this chapter. All steps of the research process were designed to ensure transparency and clarity, as well as reflexivity around my position as a researcher and potential researcher bias.

It is also important to note that qualitative research does not claim to be objective or to produce findings that can be generalised to the general population. It instead seeks to situate knowledge and provide theoretical insights. In the context of this study, no comprehensive statistics exist on the number of individuals experiencing emotional or mental distress who are using different forms of peer support. Therefore, no claims can be made on the experience of the UK population when accessing peer support. Instead insights are sought in a particular geography and setting, which is discussed further in the following section.

4.4 Research design

In this section, I explain the sampling strategy, the methods by which participants were recruited and how qualitative semi-structured interviews were used to collect data on individual experiences of different forms of peer support to enhance well-being. An account is then given of how thematic analysis was employed to extract themes and findings from the data.

4.4.1 Recruitment of research participants

For this study, a strategy of purposive sampling was undertaken in which the selection of participants had direct reference to the research questions being asked. I decided that participants would need to fulfil the following determinants:

- **Be using more than one form of peer support**

Participants needed to have experienced more than one form of peer support to be able to reflect on differences and similarities, and in doing so, provide a comparative perspective.

- **Have been using at least one form of peer support for at least a year**

I sought to speak to individuals who had used at least one of those forms of community-based peer support for an extended period to allow for depth of experience on which they were reflecting. What constituted peer support was defined by participants themselves but included self-help groups, online forums, social media groups (e.g. a Facebook support group), one to one peer support relationships and peer publications, on and offline.

- **Be living with a mental or emotional distress. This could be a self-diagnosed condition or diagnosed by a clinician.**

I decided not to restrict participants to those experiencing one mental health condition as this potentially would restrict understanding of how uses of peer support play out across different types of mental or emotional distress. Equally, requiring a clinical diagnosis risked losing insights from individuals who were using peer support to manage mental or emotional distress but had not engaged with clinical mental health services.

- **Be at least 18 years old**

The mental health of young people and children forms another substantial area of research and falls outside the scope of this study.

- **Live in London or the East of England**

Participants were sought initially in London or the East of England to try to maximise the number of interviews that could take place face to face. Other interview methods were offered when deemed necessary to maximise the sample or ensure the comfort of the participant and were kept to a minimum.

A non-probability sampling technique was applied as no robust data currently exists on how many individuals use different forms of peer support in the UK. Without an

understanding of the characteristics of individuals using different forms of peer support, it would not have been possible to develop a sampling framework from which to generalise findings to the wider population. As such, seeking those who could offer a comparative perspective of different forms of peer support was the most important factor in the recruitment of participants. This form of sampling does not allow the researcher to generalise findings to a population, however this research did not seek to explain a uniform experience of peer support. Rather, my research interest lay in generating insight and understanding and the potential transferability of findings rather than an intention to make generalisations (Guba and Lincoln 1989).

In deciding how many participants to recruit, I considered the thinking of Braun and Clarke (2013: 45), who suggest that when using interviews, a sample needs to be significantly large to demonstrate patterns, but not so large that they lose the emphasis of individual experience. Considerable disparity of opinion exists when it comes to adequate sample sizes in qualitative research, with suggested minimum requirements of 12 to 60 interviews (Bryman 2016:416). However, Mason (2010) offers a reasonably robust response with an analysis of 560 PhD studies, finding the most common sample sizes to be 20 or 30. My initial aspiration was to recruit 20 participants, whilst maintaining a consideration of points of thematic saturation.

I decided initially to try to contact participants through gateway organisations that facilitated at least one of the three forms of peer support: face to face, online or one to one support. Where possible, organisations were contacted which facilitated more than one form of peer support. This approach aimed to identify approximately similar numbers of interviewees who had experienced each of the three types of peer support. To identify appropriate gateway organisations, I built a database, initially from the Mind online directory of peer support organisations. This gave a potential of 142 gateway organisations. Groups that specifically supported young people, took place in clinical services, focused specifically on arts or creative activities or did not clearly offer peer support were removed from the list. Finally, a conversation with the national Mind team at the 2018 Peerfest conference also identified several further potential gatekeeper organisations. This resulted in a final list of 40 organisations.

Initial contact was made with several gateway organisations in February 2019. However this method of recruitment proved challenging with these organisations either failing to respond or citing existing report requirements to funders (which required organisations to conduct their own interviews) as a barrier to involvement. Some organisations also had a blanket policy which meant they would only advertise 'in house' evaluations to their users/ supporters and therefore they were not open to working with external researchers.

This led me to extend my approach to recruitment and to start to approach grassroots organisations. I also decided that, whilst it would have been ideal to conduct all of my interviews face to face, that this might restrict the data I was able to collect. Therefore I approached the National Survivor User Network and asked them to send out information about my research in their newsletter. This led to two further telephone interviews. The grassroots organisations were more responsive than the larger gateway organisations and I was able to start to recruit successfully in this way.

As my interviews progressed, I was able to consider and discuss with my supervisors who was currently represented in my sample. After identifying a gap in the sample of participants in their 20s and 30s, and with slightly less representation from regular users of online support, I decided that it would be beneficial to focus my final recruitment on individuals in this area. This led to a period of targeted recruitment in December 2019 where I contacted peer support activities specifically aimed at individuals under 25. I had already contacted a number of national online forums (Elefriends, SANE forum, Big White Wall and MentalHealthForum.net) without success. However I furthered my recruitment efforts by contacting Bipolar UK which I knew had a strong online forum and had recently released an evaluation report which suggested individuals with bi-polar were using their online forum alongside their other peer support services (groups and telephone peer support). I also uploaded my research project to the MQ research website, which allows individuals to contact researchers directly if they are interested in participating.

4.4.2 Development of an interview guide

For this study, an interview guide was developed (see Appendix Two), which covered areas such as motivations, pathways and patterns of peer support, benefits and challenges of different types of peer support and the impact and outcomes of peer support. Open questions enabled participants to bring their own meaning to the interview, to discuss what they felt was important, and to allow for the development of an account that included issues that I myself, as the researcher, had not anticipated (Braun and Clarke 2013:78). Knox and Burkard (2009) suggest the benefit of semi-structured interviews lies in their ability to facilitate comparison across cases, whilst remaining open and flexible, allowing for detailed exploration of each participant's story.

A pilot interview was undertaken in December 2018. This was with a member of the Anglia Ruskin University Service User and Carer Involvement Network and offered the opportunity to see how the semi-structured questions in the interview guide worked in practice as well as to consider my own interview style and how this could be further improved. The pilot proved very useful and led to several amendments in the interview guide. It was decided that following the introduction and before the main body of questioning, that time would be dedicated to outlining the three main forms of peer support that had emerged from the literature, with practical examples, and that a brief timeline would be built with each participant that could then be referred back to. This was to ensure clarity about a) whether it was peer support to which they were referring (rather than support provided by a professional) and b) to which form of peer support they were talking about (if they were mentioning benefits/ barriers for example).

A supervision session looking at the transcript also provided the opportunity to consider how best to keep the focus on the research question, avoid leading questions, and how to facilitate richness in a participant response. Specific strategies identified included keeping clarification questions as open as possible 'could you just tell me again...' to avoid putting specific words into the participants response, and whilst allowing the participant to bring the experience in their words to the interview, not encouraging further narrative that is off topic, but rather bringing the discussion back to the research question and interview guide. Using questions

such as 'can you tell me about a typical meeting' were also thought to be useful in developing more depth in participant responses about different types of peer support. These learnings were all fed into the subsequent interviews.

The interview guide was simplified following the initial interviews as I noted that asking about advantages, disadvantages, benefits and challenges led to duplication in responses. The revised guide had fewer questions but I continued to ask follow up questions where I felt further detail or nuance needed to be explored in a participants' response.

Interviews were audio recorded to ensure a verbatim record and audio transcribed by myself. All interviews were transcribed within one month of the interview having taken place to prompt fresh reflection.

By the end of March 2020, I was able to complete 18 interviews. The breakdown of the sample can be found in the findings chapter. The vast majority of interviews took place face to face, in community spaces such as library meeting rooms or local cafes. However, two interviews took place on the phone, and two took place using zoom software, following the Covid-19 outbreak.

All participants were sent copies of an information form and consent form ahead of each interview. Both documents were reviewed and approved by the Anglia Ruskin University Faculty of Health, Education, Medicine and Social Care Department Research Ethics Panel in November 2018, alongside the interview guide. These documents can be viewed in Appendix Three. I contacted the Faculty Ethics Panel again when I was seeking to slightly amend my recruitment approach and this amendment was approved by a Chair's action. A further approval was also required when I moved my final interviews online, because of the Covid-19 pandemic. The ethical considerations of this study are discussed in more detail towards the end of the chapter.

4.4.3 Data analysis

Data analysis needs to be both systematic and comprehensive in order to effectively fulfil its purpose to 'describe, discuss, evaluate and explain the content and characteristics' of data (Matthews and Ross 2010:317). For this study, I judged thematic analysis, 'a process of working with raw data to identify and interpret key ideas or themes' (Matthews and Ross 2010:373) to be the most appropriate form of analysis, for the way it allows the researcher to remain 'in touch' with the data, throughout the analysis (Matthews and Ross 2010:374). Further advantages of thematic analysis are its ability to provide 'a rich and detailed' account of the data and to allow for complexity (Braun and Clarke 2006: 78). Boyatzis (1998: vii) recognises that the patterns identified through the process of thematic analysis 'at the minimum describes and organizes possible observations or at the maximum interprets aspects of the phenomenon'. I felt this approach responded best to my research question, as opposed to other forms of analysis such as narrative analysis, because it would allow me to draw out themes across a number of different users of peer support, rather than focus on individual accounts.

Bryman (2016) highlights that there are also several limitations associated with a thematic analysis approach, suggesting that isolating extracts from interview data holds the potential to both remove insights from the context in which they were said, and to fragment the data, losing the narrative flow of the original account. Braun and Clarke (2006) also stress the importance of providing sufficient detail to how themes have emerged from the data as an insufficient account can deny the active role played by the researcher in the formation of these themes. In their 2006 analysis, they identify several studies where findings are described as having 'emerged' from the data, suggesting that themes simply arose and were not selected by, and seen through the lens of, the researcher. Finally, Boyatzis (1998:12) highlights several potential 'major' obstacles that might arise during thematic analysis such as projection of researcher views contaminating the data, or inconsistency within the coding process. Several strategies are suggested to overcome such obstacles, including remaining close to raw information when developing themes and codes, the development of explicit codes, involving multiple researchers in the coding process and only coding when it is possible to fully concentrate on the task.

4.4.4 Coding the data

Various approaches exist to facilitate thematic coding. These include the use of memos or framework approach (Bryman 2016:586). My process of coding the data followed the six steps outlined by Braun and Clarke (2006) as follows:

- **Step 1: Familiarizing yourself with your data** – Following my transcription of all of the interviews, I read and re-read each transcript, familiarising myself with the data and making note of initial ideas.
- **Step 2: Generating initial codes** – I started coding features of the data I thought to be interesting in a systematic manner. I then collated data I perceived relevant to each code.
- **Step 3: Searching for themes** – These initial codes were then collated into potential themes.
- **Step 4: Reviewing themes** – I then generated a thematic ‘map’ of the analysis by undertaking a process of checking to see if the themes worked in relation to the entire data set.
- **Step 5: Defining and naming themes** – I refined each theme by revisiting the data. This led to both clear definitions for each theme and clarification about labelling. I also considered the overall story told by the analysis.
- **Step 6: Producing the report** – Finally, I extracted examples for each theme and related this back to my original research question. This was then developed into the findings chapter of this thesis.

The flexibility of thematic analysis means that it can be approached in a number of different ways. This requires some further explanation of the specific way it was employed in this study. Braun and Clarke (2006) identify that thematic analysis can be conducted in an inductive or deductive way. In line with the abductive research strategy outlined earlier in this chapter, my approach to thematic analysis allowed the themes to emerge from the data. This was facilitated by the open coding

approach above which did not impose pre-existing categories or themes onto the data. Braun and Clarke (2006:81) also argue that

‘Thematic analysis can be an essentialist or realist method, which reports experiences, meanings and the reality of participants, or it can be a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society’.

For this study, analysis focused on the experiences of individuals of different forms of peer support and how they brought meaning to those experiences. It did not seek to deconstruct wider societal narratives about mental health, well-being or peer support.

4.5 Quality of research findings

Research undertaken in the positivist research paradigm has traditionally been assessed by criteria such as internal and external validity, applicability, consistency and neutrality (Lincoln and Guba 1985:290). However, such assessments of knowledge contribution are argued to be based on concepts of naive realism and linear causality (Lincoln and Guba 1985), and therefore do not serve a study such as this, which is undertaken in an interpretivist research paradigm. An alternative framework is required to assess the validity of the research findings, such as those proposed by Le Compte and Gomez (1982) and Lincoln and Guba (1985). The findings from this study are evaluated against the trustworthiness criteria proposed by Lincoln and Guba in their seminal work *Naturalistic Inquiry* (1985).

4.5.1 Credibility

Lincoln and Guba propose that consideration need be given to the credibility of the research (1985:296) and suggest that this can be achieved in two ways; firstly, through the methodology employed, and secondly by having the findings approved by those who have participated in the research. For this study, a process of member checking was employed to ensure credibility of the findings. This is suggested to be ‘the most crucial technique for establishing credibility’ (Lincoln and Guba 1985:314)

and can be both informal and formal. Informal member checking was employed throughout the interviews themselves, by using such phrasing as ‘what I understand from what you’ve said ...’ and enabling participants to respond if they felt my understanding was not representative of what they wished to convey. Secondly, and more formally, interview participants were offered the opportunity to see and comment on a copy of their transcript. Negative case analysis was also employed as a strategy to establish credibility and during the development of themes in the coding process, data was sought both to prove and disprove findings. Lincoln and Guba (1985) propose a number of further measures that can be used to establish credibility, such as triangulation and prolonged engagement. However, these were not judged to be appropriate for this study (for example, the methodology did not allow for prolonged engagement with research participants or the triangulation of different data sources).

4.5.2 Transferability

A second consideration is the transferability (rather than applicability as in quantitative studies) of findings to other contexts. Whilst Lincoln and Guba suggest that the burden of proof for the transferability of findings to new contexts should lie with the researcher wishing to apply these in other contexts (1985:298), to do so they require sufficient descriptive detail from the initial study. It is suggested therefore, that researchers should provide thick descriptions of the process they have followed. In this study, detailed descriptions were given of how interviews were carried out, the sampling process and how the data was analysed using thematic coding.

4.5.3 Dependability and confirmability

Reliability of findings in studies employing quantitative methods have traditionally been found by replication; however, Lincoln and Guba suggest that for research that is not based on naïve realism, a substitution criterion of dependability be used (Lincoln and Guba 1985:298-299). To achieve dependability, Nowell et al (2017: 3) stress the need to demonstrate that ‘the research process is logical, traceable, and clearly documented’. This was achieved in this study by developing a clear audit trail of my interview schedule, interview transcripts/ recordings and notes from the

coding process. This documentation was also made available to my academic supervisors to assure the 'confirmability' of the findings alongside consideration of the inquirer bias and that the findings came from the data itself and not my own personal constructions. Lincoln and Guba (1985:327) suggest the use of a research journal to support auditors to make judgements on inquirer bias and to trace methodological decisions made as well as personal reflections on values. A research diary was kept throughout this study and made available to my supervisors alongside other materials. This provided a clear audit of decisions made throughout the research process, and the rationale behind these.

It is important to note that demonstrating rigor in qualitative research remains a topic of some debate, with a variety of positions existing beyond the framework employed here. Lincoln and Guba's framework reflects just one of numerous approaches to establishing quality in qualitative research. Underpinning divergence between approaches is the central question of whether it is most appropriate to reject validity criteria that is linked to positivist ways of thinking or whether, in doing so, 'we are undermining the belief that qualitative research is a scientific process that has a valued contribution to make to the advancement of knowledge' (Tobin and Begley 2004:390). Morse et al (2002) contend that the introduction of parallel terminology has the effect of marginalizing qualitative research from mainstream science. They also express concerns that frameworks of trustworthiness and authenticity focus on a post-hoc assessment of quality which does not go far enough to establish rigour in research. For example, they state 'audit trails may be kept as proof of the decisions made throughout the project, but they do little to identify the quality of those decisions, the rationale behind those decisions, or the responsiveness and sensitivity of the investigator to data' (Morse 2002:16). I would contest this, arguing that Lincoln and Guba's framework does not preclude reflexivity throughout the research process. However, I also chose to reflect on the verification strategies put forward by Morse et al (2002) of methodological coherence, the importance of an appropriate sample, collecting and analysing data concurrently, thinking theoretically and theory development.

I also found it helpful to reflect on the concept of 'goodness' put forward by Arminio and Hultgren (2002), identified by Tobin and Begley (2004) as a further alternative way to consider quality of research and to move away from the language of validity.

The six steps offered a holistic and practical approach to reflecting on the quality and coherence of this study, especially the practical implications of the research, the representation of voice and the art of meaning making (interpretation and presentation). Arminio and Hultgren (2002:450) state that 'meeting the criteria of goodness requires meaning making of a phenomenon for the purpose of practical action'. In my research, I wanted not only to understand plurality around peer support, but also how this understanding could benefit those seeking to use, or facilitating peer support.

In considering trustworthiness from these alternative approaches, I aimed to ensure questions of validity were central and ongoing to my research.

4.6 Reflexivity and power in qualitative research

As part of their criteria of 'goodness', Arminio and Hultgren (2002) stress the importance of researchers reflecting upon both their relationship with participants, as well as the overall phenomenon of study. Such reflexivity involves 'exposing or questioning our ways of doing' (Hibbert, MacIntosh and Coupland 2010:48) and our positionality in the research process. Reflexivity is central to qualitative research and an interpretivist approach. However, Day (2012:61) makes the important observation that the way we conceptualise reflexivity itself and then incorporate it, has implications for the research we produce. Day explores this in three stages of research. Firstly, in the 'thinking' of research, the researcher needs to be accountable for the means by which they have come to knowledge. As I have outlined earlier in this chapter, for this study, the 'knowledge' I wished to access was composed of individual perceptions and accounts of these experiences. However, as Day argues, such accounts should be understood as particular interpretations, rather than universal truths. As such, I have positioned my study within the ontological position of constructivism.

A further important area of accountability is the subjectivity of the researcher, and how this becomes part of the production of knowledge (Macbeth 2001). Reflecting on my positionality, I identified three primary areas of subjectivity which could influence the way I gathered and analysed the data for this study. The first of these was my professional experience as an advocate for organisations in the community

and voluntary sector. Prior to undertaking my research, I had worked for two organisations, both committed to promoting and supporting community organisations. I had seen first-hand the value of these organisations, but also the struggles that many had had in recent times of austerity. As such, I considered myself pre-disposed, when listening to the accounts of those engaging in peer support, to pick up on observations that confirmed my pre-conceived notions of the inherent value of community organisations. Secondly, as someone without lived experience of mental or emotional distress, I recognised myself as 'a supportive outsider' to the mental health community. I could not draw on my own experiential knowledge. Some participants asked me outright about my own experience of depression or anxiety and this did cause me to ask myself about my own credibility as a non-peer researcher. Finally, coming from a non-clinical background offered me the advantage of not coming to the research with pre-conceived notions of how we conceptualise or define experiences of mental or emotional distress.

'Doing' is the second stage of research discussed by Day (2012:65), here paramount are considerations of the researcher-participant relationship and potential power inequalities. I was aware that by designing an interview guide, I was, to some extent, setting the parameters of the interview. However, I sought to empower my participants by asking them to define when and where the interview should take place, and by keeping my questions as open as possible, to enable participants to recount their experiences in their own words. I also offered participants the opportunity to review their transcripts or specific quotes to add further clarification or comment if they felt it was necessary. I was aware of the way I presented myself in interviews; initially, I found it challenging to move away from my previous professional persona in meetings (where often you are expected to know all the answers). Day (2012:68) reminds us that reflexivity is not a way to resolve power inequalities, however a reflexive approach did make me aware of where the power might lie in each stage of my research and the implications this was having for how I collected my data.

Finally, Day (2012:76) argues for the need of reflexivity in the evaluation stage of research. I have already talked at length about how I approached questions of trustworthiness and quality in my study, however a further reflexive consideration I found very helpful was how our desire to present a clear narrative or story in the

findings of our research can lead us to erase any inconsistencies with this narrative. To minimise the impact of this, I applied my abductive research strategy in the coding of the data and writing of the findings, presenting key findings in the original words of the participants as far as possible. I also revisited the data, actively looking for participant comments that contradicted findings, to see how prevalent these were and to ensure these were also included in the overall narrative I was creating.

4.7 Ethics

The Economic and Social Research Council define research ethics as:

‘the moral principles and practices guiding research, from its inception through to completion and publication of results and beyond – for example, the curation of data and physical samples, knowledge exchange and impact activities after the research has been published’ (ESRC 2020).

The ethics of social research has gained increasing prominence in the post-war period and has been subject to increasing regulation. However, Dingwall (2012) suggests that the principles of anonymity and confidentiality date back to early empirical studies in the 1930s. High profile cases such as Humphreys (1975), Milgram (1963) and Zimbardo (2008) have led to increasing debate around the ethical parameters of social research and the introduction of new systems for research ethics. In the UK, this first emerged within biomedical research but has now progressed across to social sciences, with the introduction of the ESRC Research Ethics Framework in 2005 and the establishment of ethical regulation committees as a condition of receiving ESRC funding (Dingwall 2012).

Ethics in social research seeks to avoid harm to individuals, communities and environments (Israel 2015). In doing so, Israel (2015) argues that it both maintains public trust and the integrity of research. Ethical research should consider potential harm to individuals, whether participants have given informed consent, whether there is danger of an invasion of privacy and whether the research can be considered to have involved deception (Bryman 2016, Diener and Crandall 1978). Harm to individuals goes beyond physical harm, and can extend to psychological damage caused by participating in research or harm caused by revealing the

identity or content of what a participant has disclosed (Matthews and Ross 2010). Lack of informed consent requires participants to understand the nature of the research and to agree to participate freely, understanding they can withdraw from the research at any time. Ensuring that the privacy of participants is maintained requires anonymity and consideration of how to protect the data generated by the research. Finally avoiding deceptions necessitates a true representation of what the research is, and how it will be conducted.

This study generated a number of ethical considerations. Firstly, the research involved interviewing human participants and held the possibility of covering sensitive topics such as the original cause of the mental or emotional distress that led individuals to seek out different forms of peer support. It was important to consider how to safeguard well-being during the interview process. For this reason, the decision was taken to access participants through gateway organisations and to provide a clear Participant Information Sheet (Appendix Four) which stated the research was voluntary. Participants were able to opt into the research by contacting me directly and completing a Participation Consent Form (Appendix Four). This also included information on how participants could withdraw from the research. During the interview, participants were encouraged to take breaks whenever needed and a list of support organisations was created and made available to participants if needed.

A number of measures were taken to ensure anonymity of participants. Interview notes and transcripts were only seen and analysed by myself and my supervisors. All hardcopy research data was stored under locked conditions and all electronic data was encoded and password protected. All participants were given a code to protect their identity and no reference was made during the audio recording to participants' names. Interview notes and transcripts were given a code to enable cross-referencing between the data. Finally, participants were informed about the intention to publish the final thesis in the Participant Information Sheet.

Consideration was also given to the impact of research on the researcher and how to protect my emotional well-being through the research process. At times, I did find the research to impact on my emotional well-being. This was primarily because several participants chose to disclose the causes for their distress in detail and it

was upsetting to hear about experiences such as abuse. Regular supervisions and contact with my supervisors were judged the best method to do this, as well as allowing space within interviews, to reflect and recover.

4.8 Limitations of the research

Because of the difficulties I encountered with my data collection, the final profile of my participants was slightly less representative of users of online peer support. The sample was also slightly skewed towards older individuals, and not as representative of individuals aged 18 – 35. I reflect on the factors leading to these constraints and wider implications for research on peer support in community-based settings in detail in the conclusion to this study.

4.9 Chapter summary

In this chapter, I situate the research in an interpretivist research paradigm and provide a rationale for the use of an abductive research strategy and qualitative methodology to explore how people use online, one to one or group peer support to enhance their well-being.

I outline the specifics of the research design, including the approach taken to sampling, data collection and data analysis. Specifically, the use of semi-structured interviews and thematic coding offered the opportunity to explore participant experiences of different forms of peer support in-depth and to generate data for how people think, feel and make choices.

I conclude the chapter with a consideration of the strategies employed to ensure trustworthiness of findings and reflexivity, before discussing the ethical considerations that emerged during the design of the study and the steps taken to ensure the research was conducted in an ethical manner.

Chapter Five

Findings

5.1 Introduction

This chapter presents the findings from interviews that took place with 18 individuals between June 2019 and April 2020. All interviews were semi-structured and explored the central research question for this study:

‘How do people who have experienced mental or emotional distress use different forms of peer support to enhance their well-being?’

Within this, the interviews sought to examine:

- Motivations of individuals for accessing different forms of peer support
- Pathways between different forms of peer support
- Types of participation and patterns of use
- Barriers to accessing different forms of peer support
- Individual perceptions of how different forms of peer support enable participants to enhance their well-being

The chapter is divided into five sections. Firstly, a brief description is given of the individuals who comprised the interview sample to provide context to the findings. The second section explores why and how people use different forms of peer support. The third section discusses how different ideas of ‘peer’ were presented by participants. The fourth section presents the key themes that emerged around how different forms of peer were considered to support participant well-being. In the final section, I outline key findings around the potential ways different forms of peer support can diminish individual well-being.

5.2 Descriptive Background

As described in the previous chapter, participants were recruited using a purposive sampling method. To be eligible for the study, a participant needed to be aged over 18, have experience of mental or emotional distress and experience of using more than one form of peer support. In total 18 participants were recruited between the

ages of 29 and 81. One participant preferred not to give her age. The age breakdown of the remaining 17 participants is given in Table Four:

Table Four: Age breakdown of interview participants

Age band	Number of participants
20-29 years	1
30-39 years	3
40-49 years	2
50-59 years	3
60-69 years	5
70-79 years	2
80-89 years	1

Half of all participants were male and half were female. Participants were also asked to give their own description of their ethnicity or background. The majority (11 participants) described themselves as White British or, in one case, White Irish. Six participants described themselves as of Mixed Heritage, British Asian or Latino/Latina.

In this study, I have chosen to employ the term 'mental or emotional distress' to enable participants to self-identify, rather than fit a pre-conceived clinical diagnosis or framework. The study's overarching conceptual framework argues that such categorisation can limit insights to be gained around the diversity of who uses peer support and for what reason. In interviews, participants described their experiences of mental or emotional distress in a variety of ways, including depression, anxiety, hearing voices, obsessive compulsive disorder (OCD), bipolar disorder (BPD), paranoia and schizophrenia. A small number stated that they rejected clinical diagnoses of mental or emotional distress, with one stating:

‘... 1 in 20 hear voices, and it’s not an illness. It’s just something that happens to some people. And it’s not something to be fearful of, in my personal experience’ (Interview 9).

The peer support journeys of participants were sometimes complex and involved intentional choices to engage with different forms of peer support. Some participants had chosen to use more than one form of peer support in tandem, whilst others had moved from using one form of peer support exclusively to another form of peer support.

Overall, all participants had experience of more than one form of peer support and six participants had at least some experience of all three forms of peer support. The forms used by each participant, alongside their age, sex and ethnicity, is represented in Table Five:

Table Five: Forms of peer support used by each interview participant

Interview Number	Sex (as defined by participant)	Ethnicity (as defined by participant)	Age	Face to face group	Online	Informal one to one
1	Male	Preferred not to say	51	x	x	x
2	Female	Mixed Heritage	60	x		x
3	Female	White British	68	x	x	x
4	Male	British Asian	31	x	x	x
5	Male	British Asian	47	x		x
6	Female	White Irish	61	x	x	
7	Male	White British	72	x	x	
8	Female	White British	29	x	x	x
9	Female	White British	Preferred not to say	x	x	x
10	Male	White British	81	x	x	
11	Female	White British	70	x	x	x
12	Male	White British	51	x		x
13	Female	White British	62	x		x
14	Male	Mixed Heritage	44	x		x
15	Male	White British	57	x		x
16	Female	Latina	69	x		x
17	Female	White British	35		x	x
18	Male	Latino	34		x	x

All of the interview participants except two had experience of attending a face to face peer support group. Just over half had experience of some form of online peer support. However, this took a wide number of forms and included accessing online forums, reading and commenting on blogs from others who have experienced mental or emotional distress, one to one email 'pen friend' relationships or use of social media. The majority of participants had developed at least one to one informal peer support relationship. One participant also had experience of working with a formal peer support worker in statutory recovery services, however as previously outlined, formal/ intentional peer support relationships taking place in medical settings were not the focus of this research.

There was considerable variety around the amount of time that each participant had used peer support, with some participants having over 30 years of experience and others having come to peer support in the last couple of years.

5.3 How and why individuals use different forms of peer support

5.3.1 Motivations for using peer support

Several themes emerged when participants recounted the circumstances in which they first used peer support. Firstly, many participants talked of the stigma or isolation they felt as a result of their experiences and how, in some cases, this led to difficulties connecting with existing social support networks. Participants also identified where they had sought out peer support following a life event or change in personal circumstance. The life events leading to this were diverse, including divorce, discharge from hospital or moving to a new country. However, what they had in common was that they led to the participant feeling a need for new or different support networks, and finding solace in connecting with peers with lived experience of mental or emotional distress. Finally, an interesting distinction emerged between those who intentionally sought to connect with peers, and those who happened across peer support as a result of seeking out support more generally. This serves as a useful reminder of the diverse ways in which people come to peer support.

Stigma and isolation

When asked what first led them to access peer support, the majority of participants talked about feeling isolated and stigmatised. For some, this was a perceived stigma of how they would be seen by others because of their experience of mental or emotional distress or accessing mental health services:

‘I think that there’s huge stigma, because you’re perceived as someone who is weak willed, who is worth pitying, who lacks discipline, who needs just to pull themselves together and to be more positive, who is lazy, there’s all this sort of thing’ (Interview 2).

'I felt very isolated at first... I thought people would judge me because I was in a psychiatric unit' (Interview 15).

The stigma described by participants was also internal and for some, came from a sense of personal failure:

'In those days there was a huge stigma but I had more of a stigma ... I was deeply ashamed ... I stigmatised myself' (Interview 11).

For others, feelings of stigma and isolation seemed to result from trying to connect and share with family or friends but feeling unable to do so. It was felt that whilst others without lived experience might acknowledge your feelings, they were unable to fully understand your experience:

'When you try and explain it to someone who isn't anxious or depressed, they try and understand but they can't, they're very much, depression and anxiety puts the person on the outside. Anyone who is related to you, on the outside, friends and family, find it really hard to understand so when you know you can speak to someone who's had a very similar experience ... it's so powerful (Interview 6).

'I'd dropped out of university because of depression and it was a kind of up and down thing in terms of really feeling ... I had friends but I felt very lonely a lot of the time. In particular I didn't feel understood. It was almost like, depression in particular, other people might acknowledge it but because it's not a problem for them, it's difficult to get anyone to take it seriously, it's almost like, yeah, it's seen as part of my personality' (Interview 1).

Varying levels of familial support

Before engaging with peer support, participants had varying levels of familial support. A number of participants suggested that their families had struggled or had been unable to support them with their experiences of mental or emotional distress. Their inability to offer the support that participants felt they needed

sometimes resulted from a refusal to accept the difficulties participants were facing or from a lack of insight into what their family member was experiencing. This lack of understanding sought participants to seek out support from those who would understand and accept them:

‘My family I saw as more of the problem’ (Interview 1).

‘My family don’t have insight into problems. See, I’ve had 21 years of therapy, and you learn more and more as you go on. I’m learning all the time. This latest therapist, she’s great, and I’ve been putting things together and understanding what’s happening. So my family aren’t supportive, aren’t loving, and they can’t be that to me, so that is not an avenue of support, or help’ (Interview 6).

‘In 1980 I was foolish enough to tell my brother that I heard voices, and he has not spoken to me since’ (Interview 7).

A couple of participants suggested that they had support to some degree from family, but that this was constrained by fears of ‘burdening’ family with their problems, or causing them distress:

‘I’ve got a lot of family around me and friends, although being depressed separates you from them. Although I’ve got my daughter and my grandchildren, when I’m very low, it doesn’t really help having them, knowing that they’re there... I realise that it actually worries her [her daughter] now, and I don’t want to burden her’ (Interview 3).

‘The only thing she doesn’t understand is the hearing voices can be hard. It’s disconcerting – for us both’. (Interview 15 describing his relationship with his sister, who is generally supportive).

Another mentioned that whilst their family was supportive, there were differences between themselves and family members in how they conceptualised experiences of emotional or mental or emotional distress:

‘In terms of my family well I suppose, the medical model fits quite well for them ... that [name of participant] is not very well [but] ... I’ve had a quite a lot of support’ (Interview 12).

A couple of participants sought support from spouses or family members, who they described as having developed considerable insight into their experiences, even though they did not have first-hand experience of mental or emotional distress themselves.

‘Oh it is different, I mean my wife doesn’t hear voices, but she’s grown over many years of knowing me, to know when my voices are bad, if I’m sitting there, sat back or something, she knows I’m fighting a bad voice, and she immediately gets me to do something, she says ‘go and do the dishes’ or something, you know, or do one of your word puzzles, I’m always telling the group that that’s something that helps me, doing a word puzzle, because you have to concentrate, whether it’s a crossword, or anything like that. I get books and books of them given to me for birthdays and Christmases, so that I can always fall back on that, and force myself to concentrate, rather than undergo the tyranny of the bad voice’ (Interview 7).

‘My mum is the best person at calming me in a crisis. You know, I only bother her when it’s serious. But you know, she is there at two in the morning and has been through an awful lot and she could probably write a book on BPD, and alcoholism and drug addiction and everything that goes with my illness, but she’s never had any experience of any psychosis, or crisis’ (Interview 17).

It is of interest that participants found it helpful to engage in peer support activities, even when they did have very strong support from family members. This might partly be accounted for by concerns that they might ‘burden’ family members or because in differences between understandings of experiences of mental and emotional distress (bio-medical versus alternative conceptualisations). Even where family relationships were very strong, some participants suggested the way in which experiences of mental or emotional distress ‘separated’ them from family members who did not have such first-hand experience.

These descriptions also suggest how participants see key distinctions between those with lived experience and those without and how experiences of mental or emotional distress can cause you to feel like an outsider. The potential for peer support to enable the creation of new social networks and social spaces where you feel you belong is explored in more detail later in this chapter.

Points of transition

A number of participants also gave examples of how they sought peer support following a specific point of transition in their lives, examples being leaving inpatient mental health services or life events, such as divorce or moving to a new country. These experiences illustrate the dynamic nature of support networks and that individuals might need different things from peer support as their life circumstances change.

One participant described how she sought out group support following a change in her family circumstance:

‘I think after my marriage broke up I was feeling quite alone, and the experience of depression is quite isolating. And I thought it would be good to go and meet other people who were going through the same thing, so part of it was a wish to socialise a little bit’ (Interview 3).

A further participant explained how she joined a service user group following her discharge from hospital, as she started to rebuild her life:

‘[I] ended up in hospital for a year, my whole life fell apart, and then came out and moved to North London because that’s where my sister lives, so basically the only kind of link. And then, I just started building my life from scratch, I was looking for housing advice and somebody put me in touch with a lady, called Jane, and said she might be able to give you housing advice, and she was running a very newly established [service] user group. And she said to me ‘I don’t know anything about housing, but would you like to come to one of our meetings’ and that’s what I did’ (Interview 13 – names changed).

Another participant talked about how he proactively thought about peer relationships to safeguard his mental well-being when he moved to a new country to study for a Master's degree:

'I realised that my source of happiness and energy is through connecting with people. So my motivation was that I knew that if I left, I left to do a masters, no, so if I left just to study and then go home, I would get depressed, for sure. So I tried to tackle that before, I want to gather with people, share with them, and then since a long time, I have realised that it's not about what you take but it's about what you give, so obviously the more people you meet, the more opportunities you have to help them, to give them, and when you give you are obviously getting out of yourself, so that makes you be distracted in a good way with other people, and that's why I like the peer because it's give and take' (Interview 18).

Intentional and unintentional peer engagement

A few participants also suggested that at the time of looking for help, they did not really understand or weren't able to give a name to what they were experiencing. This led them to feeling unique and alone in their experiences, potentially compounding feelings of loneliness:

'There are people who suffer with depression and they don't even give it a name, they don't know what's wrong with them, they don't realise it's a common condition' (Interview 2).

'I was in and out of hospital [with a physical condition] for 7 or 8 years. But all that had taken its toll mentally, so I was looking for, I needed help, I don't know, I think I knew I needed to address the issue and I didn't know what this stuff was, anxiety or depression' (Interview 4).

Whilst some participants actively sought out opportunities to engage with peers, others came to peer support more by chance, as a result of looking for support more generally. This was the case both for participants who first engaged more than 30

years ago and for participants who had only engaged in peer support in the last couple of years. This is noteworthy, given the much higher profile of peer support today than in the past and demonstrates that many individuals might still not be aware of its existence or potential benefits:

'I was looking for any help I could get really' (Interview 1 – seeking support over 30 years ago).

'I hadn't thought of peer support. But I was looking at all the different bits of support they [Anxiety Support Organisation] offered, there was counselling, books, CDs, and then I came across on the website, it mentioned that you could speak to somebody, you know peer support, by email. And I thought 'I'd like to try that'. (Interview 6 – seeking support in 2016)

'I was looking for anything that helped me' (Interview 16 – seeking support in 2006).

A few participants, even before they really knew peer support was an option, described a specific interest in meeting others with similar lived experience:

'I'd never heard of self-help groups, but this feeling, this hunger really, 'if only I could meet people like me, if people like me could get together and be friends, and just share and support each other' (Interview 11).

Within this, there is a strong sense of wanting to give support to others as well as receiving support from those who could offer genuine understanding as a result of lived experience. This suggests the importance of reciprocity as a central aspect of peer support. This is explored later in the chapter.

5.3.2 First encounters with different forms of peer support

In this section, I examine the pathways through which individuals first come to access different forms of peer support. For the majority of participants, their first encounters of peer support were either in a face to face group or a one to one informal relationship that developed in a hospital or outpatient setting. Only two participants had used online support before joining a group or developing a one to

one informal peer support relationship. Across all three forms of peer support, the majority of participants had sought out peer support independently, without clinical referral. The organic development of informal one to one peer support relationships through attending clinical services and/or a face to face support group highlighted an important pathway through which participants had developed numerous new peer relationships.

Signposting and referrals

When asked how they had first come across peer support, a number of individuals described the importance of national bodies in signposting to group face to face peer support. One member also described the support that a national body had played in enabling her to set up a new group when she first engaged with peer support in the 1980s.

‘The first thing, this would be going back nearly 30 years, looking for help during a particularly difficult time and I came across the, what was called then, [Depression Support Organisation], which I signed up to, as a member, 1991 we’re talking about, and they had a list of local self-help groups’ (Interview 1).

‘I was aware of [Depression Support Organisation] but it had a different name then, [Depression Support Organisation], it was a terrible name! But I was looking for help and I got in touch with them. And they hadn’t got anything in Oxford but in those days, it was before the days of data protection, and they just got back to me and said well there’s no group in Oxford but there are lots of people in Oxford who have depression, would you like to start a group?’ (Interview 2).

National bodies appeared to continue to play an important role signposting individuals to peer support for participants who had accessed peer support in more recent years, through online directories:

‘I think I just googled but I can’t even remember exactly what I googled or whatever but I came across the [Depression Support Organisation], which

was previously separate but now it's part of Mind, and I came across their website and saw they had a couple of support groups' (Interview 5 – first accessed peer support in 2010).

Only a few participants had accessed peer support after a referral or suggestion from a health professional, all of whom described their form of mental or emotional distress as hearing voices. In two cases, the psychologist had also been involved in setting up the peer support group:

'I was very pleased in January 2007 to join the weekly hearing voices group in [London Borough]. At its inception, the group was facilitated by a psychologist, but later that year it became peer led and early in 2008 I became a co-facilitator, and I've been there ever since' (Interview 7).

'Well basically, I'd heard about the hearing voices network through my therapist, uhm, round about the start of therapy, and she was quite au-fait, she was quite educated with what was out there. And so, I'd been going to Mind anyway, and I heard someone from the hearing voices group at Mind, I obviously heard voices from the time that I was unwell really, 20 years ago, and so I thought maybe it will help' (Interview 14).

Interestingly, one participant suggested that it was a positive experience of group therapy that gave him the confidence to seek out peer support. He was not referred directly by a practitioner, but sought out a face to face peer support group independently as a result of a positive experience of group therapy:

'Group therapy gave me the confidence to go to peer support' (Interview 5).

Some national bodies also promote online forms of peer support. One participant came across an online peer matching scheme facilitated by a national anxiety support organisation when she was looking for support:

'It was through [Anxiety Support Organisation] I think, there are two organisations, I always get them mixed up, It was [Anxiety Support Organisation] and ... anyway it was through an online website that I found,

that was willing to put you in touch with other people who had mental health issues who would speak to you via email. So that's how I found it, through a website that supports people with anxiety'. (Interview 6 – first accessed peer support in 2018).

In general, participants were more likely to access a face to face peer support group through the information provided by national bodies than an online forum. This may be partly because a number of participants accessed peer support for the first time prior to the existence of several online platforms. However, it also suggests that the profile of online support may still not be as high as face to face peer support groups. Some of the barriers to engaging with online peer support are explored later in this chapter.

Organic development of one to one peer relationships

Participants had developed informal one to one peer relationships in two main ways. Firstly, just under a third of participants developed informal one to one peer support relationships in medical settings. These one to one peer relationships were judged to be informal because they were not facilitated or set up by an external body, but arose organically as a result of accessing services at the same time. The informal peer support interactions described by participants were not structured in any specific manner but instead were flexible and formed around the circumstances and need of the peers involved.

The informal one to one peer support offered took a variety of forms. One participant described the practical support offered to her by other patients on a mental health ward:

'People on the ward were supporting me, and telling me about things, so these were other patients. And somebody gave me information about a solicitor they knew who was very understanding, and that made a huge difference to me. That really did make a difference' (Interview 9).

Another described the emotional support provided on an ongoing basis by peers during a long stay in a personality disorder unit:

‘I’ve got a lot of, because I was in hospital for so long and it was so intense, as it is with BPD and a hospital environment, those friendships and relationships intensified. So, you know I was in a 24-personality disorder, all female bedded, personality disorder unit, so the women around me all had personality disorders. And it’s probably, probably, I say the best, what I, it meant a lot having that support around you 24/7. You know, there was always somebody up, and somebody in the lounge, if you needed to chat, but yeah, it intensifies’ (Interview 17).

Another described the natural way in which informal peer relationships developed. The use of the word ‘obvious’ here suggests the way the participant saw this as a natural development of being with others experiencing mental or emotional distress in a hospital environment:

‘And was that the first time that you’d shared your experience with others who’d had similar experiences and supported each other?’

Uhm, yeah, it was apart from obviously being in the hospital when you just naturally do that because you’ve got together kind of thing’ (Interview 14).

Secondly, nearly all participants who had attended a face to face peer support group, had found that this had led to them developing informal one to one peer support relationships which provided additional support outside of the group setting. Participants described learning to support each other in different ways, for example in this group, participants stayed in touch by phone, WhatsApp and text as well as attending face to face meetings:

‘There will be telephone support in that people make friends with each other and they support each other on the phone, but that will be because they met each other through the group. And people will support each other in other ways, I suppose, WhatsApp, I think in the group people do support each other with text, email a little bit perhaps’ (Interview 2).

The social activities organised by groups also served to create the conditions by which informal one to one peer relationships emerged:

'How did it come about... well very naturally, a combination of starting to talk about things in the group and sometimes you might just continue the discussion after the meeting or in the coffee break, whatever, something like that, also because I've started facilitating the group, there's some of us that meet outside to plan the facilitation, sometimes we extend that and just go for a walk, actually that's a good point actually, thinking about it a way in which I've made friends if when someone has said does anyone want to go for a walk? And a few people have turned up and because it's just two or three of you, you end up chatting much closer. And you naturally then become closer and become friends' (Interview 5).

It emerged that the relationships that people developed transcended the group setting and allowed for additional support and more regular contact than weekly or monthly face to face group meetings:

'So I do have, made friends from there that I communicate with outside the group and one or two people, I do meet up with them outside the place and talk to them on the phone. If they haven't been to the drop-in for a few weeks, I'll call them and see how they are doing. And sometimes a small text is every helpful, it means a lot' (Interview 4).

Finally, one participant had developed three online (email) one to one relationships after peers found him listed as a facilitator for a face to face peer support group:

'They all approached me, by chance' [through the Hearing Voices network] (Interview 7).

This demonstrates the way in which attending or facilitating a face to face peer support group has the potential to link you to a wider peer network.

Another participant who described how attending her first peer support group led to her involvement in a number of activities around mental health, including taking part in a national steering group:

‘All from that first group, a bit like waves, which was great, went out from there really. I mean that is how I started to get involved in everything, ultimately it’s how I got involved with [National Mental Health Campaign]. I was service user representative for 15 years at the [National Institute], that’s how I got involved in everything really. Once you get involved in one thing, you hear about more things, and they’d mainly be campaigning projects of organisations, but within that people were, you know if one person wasn’t well, or people were upset, you perhaps get together at lunch time and have a little, I suppose that would be peer support, so it was all mixed. But it was very much being part of a community’ (Interview 11).

The way in which peer support enhances the social network of individuals who had experienced mental or emotional distress is explored in more detail later in this chapter. It is of note that the informal one to one relationships described by participants had developed through very specific pathways. This suggests the potential difficulty of connecting informally with a peer on a one to one basis if the initial encounter is not facilitated through attending inpatient or outpatient mental health services or attending a face to face peer support group.

5.3.3 Patterns of participation

Numerous similarities and differences became evident in the way participants engaged with, and participated in different forms of peer support. This section describes how for some participants, different forms of peer support have become part of a regular routine. Consideration is given to how participants perceived face to face peer support groups as an ongoing insurance policy or safety net, but also often used online support in times of significant distress. Participation was more active in some forms of peer support compared to others and participants talked about how some forms of peer support encouraged them to give more, or contribute more, to others over time. Finally, some participants combined different forms of peer support in order to tailor the support they needed and this offers the opportunity to further uncover some of the unique uses of different forms of peer support.

Peer support as part of a regular routine

Across all three forms of peer support, examples were given where peer support had become a regular, and sometimes significant part of the day to day life of participants. This was most apparent from the way in which many participants attended a face to face peer support group on a monthly basis. A few participants had accessed groups even more frequently, on a weekly basis. For a small number of participants, this was a pattern of regular participation that had endured for more than thirty years.

'I've been going regularly to this one self-help group, most months since 1995 to 2019' (Interview 1).

'It's 40 years now since I went to my very first local self-help group' (Interview 11).

'We've met without a break from 1997. It got to the point where it was so large, we had to have a second meeting' (Interview 2).

A couple of participants had sought out even more regular engagement, saying that they felt a monthly group wasn't frequent enough:

'I found one of the groups and they said they only do it twice a month and I was looking more for a weekly thing' (Interview 4).

'I wish I had a group everyday but I don't.' (Interview 16).

It is of interest that, whilst several participants had attended the same group for several decades, others had dipped in and out of different groups over a number of years. The reason for stopping and starting again was either because the face to face group they had been attending had stopped meeting, meaning they had to find another group, or because they had found themselves in need of additional peer support because of a period of increased mental or emotional distress.

'I think I stopped going because either it stopped, you know, [the facilitator] got unwell for a bit, or I can't remember but then I went to a different one ... and then I went to one in [London Borough], wanting to carry on, and that was a bit different, I didn't connect so well with the people there. But I've recently been back in the last few years and have connected with them very well, so ...' (Interview 14).

'I started going to local groups, last year or the year before, I felt very unwell again... just to be there with people who have mental health problems, it was helpful to a degree' (Interview 11).

Only one participant described a gradual reduction in their frequency of attendance as he had started to feel less need for peer support. He still attended groups every few months as a facilitator:

'I used to go, when I first started [8 years ago], every month, now I probably go every three months, every four months, so a lot lot less... I think it was for two reasons. Number one for myself, because I was just coming out of the depression, and probably more worried about needing the insurance policy, and probably secondly I didn't have as much going on in my personal life, as I did then, so it was easy to free the time, whereas now it's not so easy' (Interview 5).

For a small number of participants, online peer support had come to form part of their day to day life. One participant described how he used online peer support (Facebook groups) on a daily basis because he was no longer able to access face to face groups because of health reasons. Another participant was still attending a face to face group weekly but had also developed several online peer relationships which he maintained through regular email exchanges. This participant felt that he would continue to attend the face to face groups as long as his health would let him, but then would continue to use online peer support even if he was no longer able to attend the face to face group.

'I've become less and less able to get out so I reply on computer contacts and that really is my peer support, through that' (Interview 10).

‘I can do that even if I’m housebound. I can sit at the computer’.

(Interview 7)

These participants were both retired and experiencing physical health difficulties which, to varying degrees, had impacted on their ability to meet with peers face to face in a group setting. Whilst these participants did not explicitly articulate that developing stronger social connections led them to use online support with more regularity, there was some indication that they had formed relationships online. Others, who had engaged with less regularity and less actively with online peer support had not formed relationships in the same way. Further research is needed to explore how the development of strong social connections encourages individuals who have experienced mental or emotional distress to engage with online peer support on a more regular basis.

Informal one to one peer support relationships were also an important part of the weekly life of several participants. It was evident that for some individuals, seeing one to one peers had formed an important part of their social network and weekly activities:

‘Yeah, we see each other every week, on Fridays we see each other. He used to come to the [peer support] drop-ins but now he comes afterwards, to the pub. So we meet every week or talk on the phone, so it’s, think so, that’s there from ... that person was doing better and that time, and then he wasn’t doing so well and then I was there, he was calling me every day, I was trying to calm him down. Now he’s doing fairly well. It’s a good feeling when someone needs your help’ (Interview 4).

This highlights the importance of informal one to one peer relationships as new social connections for individuals with experience of mental or emotional distress. The impact of such opportunities to develop new social networks through different forms of peer support is explored later in this chapter.

Support in times of distress

It is of interest that online support seemed to play a particularly significant role for participants in times of distress. A number of participants described calling on online support in response to low points:

‘If I’ve had a bad day, it might be ... it could also be during lonely weekends or oddly, it might be the thing that’s on your mind when you go into work ... because you’re quite wrapped up with the issue. There might even be times on occasion when I’ve been posting from work. So, it would be times when I thought I was going into a dip’ (Interview 1 – describing online forums).

‘Well if I came in, and I was feeling particularly bad, I would email her, and we’d just have a brief conversation by email’ (Interview 6 – describing one to one email exchanges).

When it came to face to face peer support groups, some participants had found it helpful to continue attending a face to face group, even in times of mental or emotional distress:

‘Some days I would be having a bad day and I’d only just make it to the group, just force myself to go, and then the nice thing about the peer support is that people, they can tell when you’re having a really bad day because, you know, you look really closed down, or you’re talking to yourself really weirdly or something, you know, and then you would be given time within the group, to discuss, what’s the problem, why are you struggling? You know, what’s your experience at the moment? And then I would explain that one of my voices was being particularly difficult and challenging’ (Interview 14).

However, others also mentioned that during times of mental or emotional distress, they felt unable to attend a face to face group and needed to withdraw:

‘If you’re very depressed, you’re probably not going to be able to come to a group’ (Interview 2).

‘I’ve had bad bouts of depression, where I can’t do anything, and there’s a point there, when I start the cycle of depression, I have to shut myself away, and I can’t talk to anybody, so peer support wouldn’t work with that’ (Interview 10).

Sometimes groups were still able to reach out to individuals in this situation, suggesting the extended support offered by face to face groups, beyond the meetings themselves:

‘We have got people who are feeling very depressed who don’t come to the group, and sometimes we give them some support at home’ (Interview 2).

Only one participant described their one to one informal peer support relationship explicitly as a safe haven in times of need:

‘When things were really bad she would say just come up to the house and I went, just to have someone around, just to be not on my own, because I wasn’t in a family. It almost didn’t need any words, it just needed someone to be accepting and to understand’ (Interview 2).

This section has identified two important patterns of participation; using peer support as an ongoing safety net and reaching out at times of distress. These patterns vary across forms of peer support and these differences are important when it comes to the contribution of peer support to individual well-being. How well-being is related to the regular engagement with peer support over long periods of time is explored later in this chapter.

Active and passive engagement

In Chapter Three, I introduced the idea of participation in peer support being ‘active’ or ‘passive’, for example attending a face to face group and choosing just to listen rather than share your experiences, or reading online forums but not writing about your own experiences. In this section I describe several findings that emerged in relation to how ‘actively’ participants engaged with different forms of peer support. Firstly, that participants described their engagement with online peer support as

generally more passive than their engagement with other forms of peer support. Secondly, participants described how patterns of participation were not static but, in some peer support environments, progressed from quite passive to more active forms of engagement. This was a pattern that was particularly clear for face to face peer support groups. Online peer support offered fewer opportunities for progression and this led to some participants ceasing their involvement. Informal one to one peer support relationships were described as balanced over time, with those involved finding a natural equilibrium between giving and receiving support.

Generally, the engagement with online support described by participants was more passive than engagement with face to face groups. A number of participants described how they liked to visit and read the content on online forums but that often didn't actively contribute in the same way they might in a face to face peer support group. However, reading about the experiences of others and knowing they were not alone in their experiences still offered a degree of comfort and reduced a sense of isolation:

'I haven't actually subscribed, you know, comment back, perhaps I should, but I've read the comments and I've thought 'oh phew! That's really helpful' (Interview 11).

'Interestingly enough, I use online forums for myself, but I don't go onto online forums to support other people, which I've just realised while I'm talking' (Interview 8).

Several participants also described difficulties contributing to a face to face group at first, and as a result choosing to engage more passively:

'I had trouble contributing at first' (Interview 1).

'...it was good because they immediately stated that it was confidential, but it took an awful long time before I really shared anything' (Interview 12).

However, where this differed significantly to online peer support was in the way in which this changed over time. Several participants described a process through

which they had gone from needing support to also feeling able to help others in the group. For several participants, notably those who had engaged with face to face peer support for a number of years, this had led to them taking on a role as a facilitator of a face to face group:

‘Now I’ve joined the committee ... within the small group each person has 5 minutes and often when it comes to my turn, often, I don’t feel the need to speak, that I’m coping alright, and that I’m more in a role of helpful others’ (Interview 3).

‘I would, because when I first came, I didn’t have anything to give, I needed some support, now I feel better, healthier’ (Interview 6).

Being able to give more in face to face peer support groups was an important aspect of the ongoing recovery journeys of individuals and illustrate the importance of different forms of peer support being flexible enough to accommodate the changing needs of individuals over time. It is of note that a small number of participants suggested that they stopped using online support specifically because they felt that they had exhausted the support they were able to receive from this form of peer support:

‘...after a while, I didn’t like it because it’s the same, so I stopped. I thought, this has done all the good it’s going to do me’ (Interview 4 – after using an app).

‘I’m just trying to think why I stopped. I suppose there’s only, maybe we sort of exhausted; I’m trying to remember the conversations we had over email. I suppose I felt it had run its course, the person couldn’t necessarily help me with what my problem was, so it wasn’t quite what I needed I suppose, it was a bit of a relief but it wasn’t quite what I needed’ (Interview 6 – after using a one to one email peer exchange).

When it came to informal one to one peer support, a number of participants described these as very balanced and with equal participation between themselves and their peer:

‘...it’s interesting because our depression often doesn’t coincide, so if one’s alright and the other one’s depressed, we sort of, support each other like that and we go out together’ (Interview 3).

One participant gave two very thought-provoking examples of where they have found a one to one peer support relationship and a face to face peer support group had not supported their recovery journey. This unique contribution further suggests the importance for all forms of peer support to be able to accommodate the changing needs of individuals as they process their experiences of mental or emotional distress:

‘So for example, if you’re in a situation where somebody, and this is definitely what I experienced, I had a friend who was very very supportive, who had some similar experience, and who really was my closest friend, really looked after me, really cared for me when I was having a breakdown. When the breakdown finished and I was going into recovery, I changed, in terms of my boundaries, I didn’t need rescuing, so our relationship changed, because she no longer knew who she was supposed to be in this relationship. And it completely fell apart’ (Interview 8).

‘...the reason that I left on both times was because I wasn’t able to change in the group, because they stayed as negative, in my perspective, so they were like ‘this is really difficult’ or ‘this is a struggle, blah blah blah’ and I was coming in, I’ve actually made progress, I want to talk about I’ve just discovered running’ (Interview 8).

Understanding the ways in which individuals engage with different forms of peer support provides important context to the perceived contribution that each form makes to individual well-being.

Combining different forms of peer support

As previously mentioned, peer support journeys were extremely varied and some participants had progressed on from one form of peer support to another, whereas others had chosen to use a variety of forms of peer support in combination. The

majority of participants, 14 out of the total of 18, had some experience of using different forms of peer support in combination. Where participants used online in addition to attending a face to face peer support group, they did so for a variety of reasons. One participant described how she looked for support from peers online when she was unable to find a shared emotional response from a group:

'If I can't find anyone who I know, from all these types of support, who've had something specifically... I just google it... I tried to discuss it in a [face to face peer support] group but I just got blank stares... people often don't understand me, so I go online and then find that there's been people who've been troubled by these things, and certainly people that on the mental health blogs, there's people that are troubled by quite abstract things. But I find it so helpful' (Interview 11).

Several examples were given of where online contact could help enhance the impact of face to face group peer support. One participant used online networks to find out where she could access a face to face group when away from home:

'You can use Instagram, WhatsApp to find out where your nearest group is. So I actually went to one when I was at a particular festival, in another country, it was through WhatsApp that I was able to plug into a face to face group' (Interview 8).

Some participants also used social media platforms such as WhatsApp to keep in touch between meetings, or when they were unable to attend face to face group meetings:

'It's nice and then sometimes face to face, they may not see each other, but on WhatsApp they got communication, cos some people can't come every week, so, to have that, it's a very useful thing you know' (Interview 4).

Many participants attended a peer support group and had ongoing informal one to one peer support relationships. One participant described how even after developing strong one to one relationships, he still found going to a group helpful because of the opportunity to gain new insights:

‘You meet new people and you get fresh insights, because different people have different ways of seeing it’ (Interview 14).

The way in which participants curate and call on different forms of peer support in response to their own needs and circumstances demonstrates the unique value or contribution of online, one to one and group face to face peer support. Face to face peer support groups appear to offer individuals particular opportunities to move through different forms of progression. It is perhaps for this reason that face to face peer support is most commonly that which becomes part of the daily routine for individuals. The accessibility of online support is beneficial particularly to individuals in times of distress but does not lend itself in the same way to extended periods of engagement. The impact of different forms of engagement on the well-being of individuals who have experienced mental or emotional distress is explored further later in this chapter.

5.3.4 Barriers to engaging with different forms of peer support

The majority of participants that took part in this study were still actively using peer support and intending on continuing involvement into the future, as such these interviews did not offer so much insight into the reasons why individuals stop using peer support. However, several important findings did emerge around why participants had chosen not to engage with specific forms of peer support. Although not ultimately a deterrent to the participants in this study, a number did mention that they had pre-conceptions before attending a face to face peer support group and questioned whether they ‘fitted in’ when first attending, because of the makeup of existing group members. The strongest reasons for not engaging with online peer support related to its ‘faceless’ nature and the fact that you could not know who was behind the screen, as well as some fears around platforms such as Facebook and how they might use your personal data. The theme of social anxiety as a barrier to attending face to face groups was also raised and given as a key reason why someone might choose to access online rather than face to face support. Both of these potential barriers relate to the unique communication styles offered by each form of peer support, a topic which is discussed in more detail later in this chapter. Finally, comments from a couple of participants highlighted the time and space needed for informal one to one relationships to develop. This is significant because

without sufficient opportunities to develop trust, these relationships might not have a chance to emerge.

Pre-conceptions and 'fitting in'

Participants described a specific experience relating to face to face peer support groups, in that, before attending, or when attending their first group, the group make-up did lead them to question whether they 'fitted' with a group. This was generally when the age or gender of group members differed to their specific circumstance:

'You kind of have the stereotypes of who is going to be in a depression or autism group but then people turn out to be nice, and intelligent and you kind of think, actually, if all these people around me are okay, maybe I'm okay as well' (Interview 1).

'I went with an open mind to be honest, but it was on the bottom floor, and I've seen through and I went up, and then I had to come back down. But when I saw all the people, fifties, I thought 'don't tell me that's the group', so then I went upstairs, and it's downstairs, then when I went in, I was the youngest but people were very nice actually and first I was like, I'm like odd one out, but then soon, you just need one person to connect with, and I connected with one person and that person connected with me, he's a very good friend of mine now, he helped me to feel welcome and once I felt that comfort, it was okay' (Interview 4).

Whilst for these participants, pre-conceptions and initial impressions had quickly been overcome, there was an acknowledgement of a pattern across face to face groups that many individuals came to an initial meeting but never returned:

'There are people who don't find the group helpful. If you look on the website, you'll see some of our annual reports and if you look at the number of referrals, compared with the number who come to a meeting, a lot of people write to us, and of that, only a small proportion come to a meeting. It's got a bit better because we now offer people a one to one before a meeting and that has helped, because a lot of people feel anxious about

coming. But of that, when people do come to a meeting, again, a lot of people come only once, or maybe twice, and they never come back. So obviously, it doesn't meet everybody's needs' (Interview 2).

Whilst the reason for this was not known, the comments of participants above suggest that when individuals feel themselves not to 'fit in' with existing group members, or fail to make an initial connection in that first meeting, this might lead them not to attend further meetings.

Fear of 'faceless' mediums and personal data

Barriers to using online support included lack of confidence using computers and engaging with people online. Several participants across also described fears around personal data:

'I would not want to share my personal experiences on Facebook at all, knowing what algorithms, they might for example, start showing me adverts for anti-depressants for example' (Interview 1).

No obvious pattern emerged as to whether this was a particular concern for participants of a certain age or with particular experiences of mental or emotional distress.

Concern around 'faceless' mediums of peer support was also a topic of some discussion at a London-based face to face peer support group I attended in July 2019.

Research Journal Entry, July 2019.

'I was really surprised today how much people talked about not knowing who was on the other side of the screen and how worried that made them ... the literature on online support had made me think that anonymity online would be a big bonus to people and make them feel able to disclose how they were feeling more easily but that didn't seem to be how people were feeling at all'

Others simply stated that they didn't really know what online support was available or that they felt themselves to be more of a 'face to face person', preferring to communicate via a face to face medium. This general low level of awareness of the forms of online peer support is of interest, especially when so many online options are now available. A couple of participants suggested that accessing online peer support was really an option for those who felt unable to attend a face to face group or as a stepping stone to attending a face to face group:

'I think for me, it's more my medium, I prefer face to face, yes, I just find it a deeper sort of experience, you're physically there, it's a little bit detached isn't it emailing someone, because you don't know what they look like and what they're really like, you try and judge them from what they type and you can easily misconstrue, you know how people misconstrue text, although I didn't have that problem, but face to face is my medium' (Interview 6).

'I just never thought of it really. I think as we discussed a little bit in the meeting, I can see it making sense if you didn't have, you know, people who were worried about coming to a meeting, perhaps with social anxiety or whatever, it's a very powerful thing, a very useful thing and maybe it'll be helpful. But because I had already had that group therapy, which gave me the confidence to go to group support, then not really a need for it' (Interview 5).

Social Anxiety

Social anxiety also emerged as a potential barrier to attending face to face peer support groups. One participant, who also had over twenty years of experience of facilitating groups, described how some fellow participants had struggled to engage with the group as a result of this:

'We seem to have attracted a number of young men, who are on the autistic spectrum... and they suffer quite a lot with social anxiety, and depression, it goes alongside with the condition. And one of the problems they've had is because of their high degree of social anxiety, they've found it hard to come to the group' (Interview 2).

Interestingly, a small number of participants who were interviewed as part of this study described themselves as socially anxious but had not found this to be a significant barrier to engaging with a face to face group, rather they had found the group peer support environment a useful space to develop social skills and confidence.

Space to develop one to one informal peer relationships

The vast majority of participants had experience of an informal one to one peer relationship which had developed either from being with others in a clinical setting or from attending a face to face peer support group. No specific barriers were mentioned with regards to informal one to one peer support relationships. However, one participant did mention the importance of social events in creating the time and space for these relationships to develop. Another participant who had been attending a face to face group for about a year but had not yet developed this kind of relationship explained her hesitation. Significantly, her reason not to have a coffee with a peer following an early meeting was related to her own doubts around having something to offer a peer at that time. Although now she feels stronger and that she would like to connect, she questions whether someone would need 'a depressed friend' outside of the group setting. These comments illustrate the complexity that can exist around developing informal one to one peer relationships and that it is not always easy to move a relationship outside of the group setting:

'I haven't so far, I mean at the end of the session ... they do go to the pub, there's a bit of a social element. But one girl, who I get on with very well, she always goes off quite quickly, and I didn't want to, I mean maybe she thinks 'I don't need any depressed friends' (laughs) but I don't know, and when another lady, who I hope I see again, I would, because when I first came, I didn't have anything to give, I needed some support, now I feel better, healthier, there's a woman who has a son who's schizophrenic, and the very first time we met she said 'Oh do you want to go for a coffee' and I said, 'oh I've got to get back' ... not thinking that she might want to speak to me about my experience with a schizophrenic sister. So I thought, next time she's there, I'll say, 'do you want to go for a cup of coffee, and we can discuss it', because she's depressed, and her son has schizophrenia' (Interview 6).

This participant had been attending the group for around a year and a half, comparatively a very short period compared to a number of participants who had decades of experience attending groups. This suggests the time that it can take for one to one relationships to develop, a finding which was also illustrated by the description a further participant gave of how he had formed two important one to one peer support relationships:

'I started to see Jack every weekend, on a Sunday, it was probably more than a year actually, I would have said it was maybe two years, I went to [National Mental Health Support Organisation] overall for about 4 years. And the last two years, me and (name) were very close. And then Terry turned up on the scene about a year into that. So maybe we're talking about six years ago. And uhm, he didn't, he wasn't a good friend at first. But when he became, you know when he started to do the band with us, that's when we became good friends, and now I see them both every week' (Interview 14 – names changed).

5.3.5 How peer support is used alongside professional support

In order to understand how different forms of peer support were used alongside professional health services, participants were asked how they felt the support they received from peers was similar or different to the support they had received (if any) from professional health services. This revealed a number of important themes. Firstly, whilst the majority of participants saw peer support as complementary to professional health services, a small minority felt strongly that engaging with peer support had provided them with an alternative to professional health services. A few participants, both those who had engaged with medical services and those who had tried to avoid them, described the fear and lack of trust that often comes with disclosure to those perceived to be in a position of authority. Finally, a number of participants commented on the importance of the different knowledge bases drawn on by professional and peer support. This had implications for how well medical professionals were able to understand and empathise with their experiences and influenced how individuals were able to conceptualise and process their experiences of mental or emotional distress.

Peer support as a complement/ as an alternative to professional support

The majority of participants used peer support alongside a variety of forms of medical support including seeing therapists, psychologists and psychiatrists, GP support and attending group therapy sessions. Many saw both professional and peer led approaches as having something positive to offer their recovery:

‘Well, I suppose the peer support supplements, or for me, is supplementing the therapy I’m having, as well as the medication I’m taking, and as I say, I’ve got to the point where I’m feeling well enough to give something back to others’ (Interview 6).

‘[Group therapy] was really really good. And it made me understand that I was depressed, that it was symptoms of depression, all this wacky stuff in my head, I was thinking is this really happening or is this in my mind? I realised it was in my mind, and why it was in my mind, and I got better. And from that I actually realised that one of the things historically is that I hadn’t talked to people, I’d been the kind of person maybe who you do read as a bit of a male trait, you don’t talk to people, or you bottle it up or whatever, so I realised it’s good to talk, as the saying goes’ (Interview 5).

‘... [the] medical model, it’s true, so it says things about the brain and says things about the mental formation, and the chemical, you know, experience of the brain, that is helpful to me. So if you think okay it’s adrenaline and cortisol, and a mixture of that causes me to get over-worked, and that ups the regulation of my nervous system, then it’s helpful to know all that, because I don’t respond, I got angry about something, but it’s just fight or flight kicking in, and therefore I don’t have to go down that road, I know what it is... and then how that works with the recovery model is that my particular take on this, is that when you know what it is, then it helps to know what not to do ... if you know what to do, there are so many things you can do, whether it’s mediation, mindfulness, going to a hearing voices group ...the recovery model is that sort of way of accepting yourself as you are, not thinking you’re broken, not thinking you’re wrong, not thinking you’re a terrible person because of these things’ (Interview 14).

Several participants talked about how therapy had allowed them to offload and process their feelings in a way that had not been possible in a peer support group because of the lack of time for each individual to share in great depth.

'Well, I was actually seeing a therapist for a number of years and that was very helpful because it gave me a lot of time to offload what I was feeling. And my therapist would put it in perspective and it would give me the strength to carry on for the next week. Whereas with the group, it's not so in depth, you know, you only get 5 minutes to talk about yourself and the other people have shared your experience so it's different in a way. So a therapist is sort of a professional that's helping you, like being much more objective, that's the word. Whereas being in the group, it's much more subjective, the others can empathise with you' (Interview 3).

However, a small number of participants, with varying experiences of mental or emotional distress saw peer support as a way to actively avoid engaging with clinical support. For these participants, peer support had given them an alternative and an option not to engage with traditional medical treatments:

'I find that by having peer support, I can manage to do that [avoid disclosure] which is really important... I can manage without, I don't want, I don't need to have psychiatry. I'm ambivalent about psychiatry ... peer support has enabled me to steer clear of psychiatry' (Interview 11).

'You see, I think it's an alternative, it's about having a choice. So it is an alternative, and it's about prevention as well, if you have the support network there, and you can talk openly and freely, without any risk, of being sectioned, or it going anywhere at all, then that in itself is a positive thing I think' (Interview 9).

'I remember walking into that meeting all those years ago, because it was an alternative... all the time I was on the Mental Health ward I refused the drugs' (Interview 9).

Lack of trust

Again, a small number of participants mentioned a fear of disclosure to medical professionals, because of the potential repercussions. This was voiced in fears that GPs would escalate their case to a crisis team or that they might be 'locked away'. These fears were not explicitly based in past experience but rather what they feared might happen, rather than what had actually happened to them in the past. This demonstrates the very real fear some individuals have that they will lose freedoms or control if they disclose the full nature of their distress and led participants to be selective about what they disclosed:

'I've never ever told any medical professional everything about my mental ill health, I've only told them enough to get a sick note or to get medication' (Interview 11)

'When I used to go to the GP, I would always be selective of my words because I knew, if I really tell the GP how I felt, he's going to call the crisis team or something'. (Interview 4).

'But I never dared to admit to anyone there that I heard bad voices that tried to control me. I was too scared they would lock me up permanently and throw away the key'. (Interview 7).

The importance of different forms of peer support in providing a safe space where individuals can disclose their experiences without fear is explored in section 5.5.4.

Competing forms of knowledge

Participants also described how they found the framing of their individual conditions into a bio-medical model and the subsequent positioning of 'expert' and 'patient' difficult for a number of reasons. One participant described how the pre-conceived frameworks employed in group therapy meant that it was impossible to share his understanding of his experiences:

'I was going to this NHS group psychotherapy group for three years as well and they were 90-minute sessions I think and I almost can't believe how unhelpful it was. I think it was partly that it's sometimes difficult to get a word in edgeways, or talk about the things that are really on your agenda. And I find that's easier in a face to face [peer] group, or an online [peer] group, in those cases you can dictate the agenda and what might be called the framing, so if you're meeting a clinician it will be 'oh are you sleeping well, what's your eating like, how long has it been going on?' and those kinds of questions. It doesn't give you the room to actually tell your story in the way you want to tell it. Even in three years of group therapy, they said 'oh in a few weeks, we'll start talking about things in a narrative way, you can tell bits of your story, you know', but I never did, I don't know why not. It was a promise that was made and it wasn't kept' (Interview 1).

Another participant had found the pre-framing helpful as a way to understand his experiences of mental or emotional distress:

'It was usually very structured, it was professional therapy rather than peer group therapy, in that the therapist wouldn't have a particular plan in mind, it was a bit like a lesson, you know, where you go out and do these things, the idea is then you realise yourself 'oh my god, look, a common theme about us all, is that we tend to be perfectionists, is there some connection between that and depression?' (Interview 5)

These distinct experiences highlight the different ways in which individuals' process and conceptualise their experiences of mental or emotional distress. For some, the pre-framing offered by bio-medical approaches is helpful, but for others, it can act as a barrier, making it difficult for individuals to tell the story of their experiences in a way that makes sense to them. How different forms of peer support enable individuals to process their experiences is explored in more detail in section 5.5.1.

Several other participants also emphasized the limitation of support which is based on theoretical and studied, rather than experiential knowledge:

'I've sometimes been shocked at what psychiatrists can say to people. All your training and whatever but with a day of depression yourself, maybe you'd understand' (Interview 2).

'They've got their textbook but nothing else' (Interview 17).

'I do think everyone will look at psychiatrists as if they are the experts in mental health and in many ways I feel they're not, I mean people are realising it now, whether they are realising it deeply, people who've been through stuff are experts on their own condition ... I'm willing to accept that someone knows as much about the subject as I do. I'm less likely to accept that they know more about me than I do, which is what it sometimes feels like' (Interview 1).

This sometimes led to feelings of frustration with health professionals because it was felt they were unable to offer real understanding of their experience. Examples were given where health professionals made judgements of well-being based on superficial appearances or used inappropriate language:

'People keep assuming from the appearance 'Oh, he's alright'. And which is like, really? It can be, I know, I get it, it's what all of us do but it can be frustrating because you want someone to notice what's behind the face' (Interview 4).

'Well, most of them simply don't understand me, the experience of hearing voices, perhaps I'm being unfair but they tell you, 'this is just an intrusive thought of yours', you know, when I know it isn't because I get intrusive thoughts, we all get bad thoughts, don't we, that we'd rather not own, but you do get them. But I know them. Voices are alien, they are alien things, you know, out of my head. They're quite different and I know the difference' (Interview 7).

'...be positive, it's not so bad, you'll get over it' ... professionals say all these sort of things, thinking it makes you feel better, and it doesn't' (Interview 2).

This is in contrast to the real understanding that many participants had found through accessing different forms of peer support:

‘... you are able to be totally honest, and just get the understanding and you get empathy, sympathy and you’re not being judged, you’re not being misunderstood, and people aren’t saying ‘Oh dear’ and not knowing what you’re talking about, never knowing or having experienced it.’ (Interview 6).

This suggests the importance of authentic understanding in reducing feelings of stigma and isolation, thereby contributing to individual well-being.

5.4 Conceptualising Peer Support

Throughout the interviews, there was a guiding idea of ‘peer support’ and how this differed to non-peer or professional support. Within this, a number of important themes emerged. Firstly, the complexity and evolving nature of what could be considered a form of peer support and the blurred boundaries between the possible categorisations of ‘face to face group’, ‘online’ and ‘one to one’ peer support. Secondly, ideas of what constitutes ‘shared experience’, with participants describing experiences of mental or emotional distress as unifying but only within certain parameters, with some face to face groups drawing clear boundaries around what kind of experiences of mental or emotional distress could be shared in the group setting. Finally, ideas of peer friendship and the terminological complexities around peer support highlighted the importance of exploring what terms were meaningful for participants, and which do not perhaps commonly appear in policy discourses.

5.4.1 Complexity of the peer support landscape

‘It doesn’t have to be people sitting around in a circle for it to be peer support’ (Interview 4).

Participants were invited to take part in interviews if they had experience of more than one form of peer support. Going into the interviews, I had thought it most likely that participants would be attending a face to face peer support group, using an

online forum such as Elefriends or perhaps working with a volunteer peer support worker, from a charity on a one to one basis. However, what I found was a far more complex picture of the forms of peer support individuals engaged with. Alongside monthly face to face groups, conducted on more traditional models of the sharing circle, participants talked about weekly face to face drop-ins, which were far less structured sessions. Participants also identified online support to take the forms of Instagram posts, WhatsApp groups, discussion forums, skype meetings, and reading/ responding to blogs written by peers. The importance of informal one to one peer support also became very evident, with nearly all participants having direct experience of this. Participants also talked about the role that writing and receiving letters from peers had played in their well-being, as well as receiving newsletters written by peers. This highlights the increasingly varied ways in which individuals with lived experience of mental or emotional distress exchange support and the plurality of peer support individuals draw on, to support their own well-being.

It also became evident that it was difficult to strictly delineate between the three proposed categories of online, one to one and group face to face, as several forms of peer support could be considered more than one of these. One example being a participant who wrote emails to international penfriends on a one to one basis, sharing experiences of hearing voices. This could be considered both a one to one and online interaction. Another participant had been part of a skype peer support group, which could be considered both a group face to face interaction and online support. Finally, many forms of peer support were intertwined, with members of a face to face peer support group also forming informal one to one relationships and using online forms of peer support, for example WhatsApp groups to build and strengthen the relationships formed in the group environment. I will reflect further on the challenges of categorising peer support and implications for future research in the discussion chapter of this thesis.

Formal and informal peer support

The majority of participants did not have experience of the formal one to one peer support discussed in the contextual chapters of this study. However, two participants did speak specifically about the tensions between formal and informal peer support. One participant questioned the lack of reciprocity in more formal forms

of peer support. They felt that peer support had to be a relationship between equals and as such, did not view peer support workers within their definition of peer support:

‘To me, the social concept of peer support is the same as mutual support, as a concept its mutuality and reciprocity between equals and no hierarchical structures ... but then I realised its being used in other ways... I mean people are getting qualifications as peer support workers and I’m thinking that’s not peer support’ (Interview 11).

Another emphasised the tensions that have emerged by introducing more formalised position as paid peer support workers:

‘I have friends who get paid as peer support workers, I’m happy for them and they seem happy doing it, but other people feel more conflicted around that ... (Interview 9).

This participant also described how she felt that the idea of peer support, which had emerged from a grassroots movement, had been somewhat co-opted by the introduction of peer support workers into the mainstream health system:

‘Sometimes there’s a good idea at the grassroots, in the community, and somehow that gets absorbed into the system and transformed into something completely different’ (Interview 9).

It was of interest that formal one to one peer support featured so little in the experience of participants, given the high profile of this form of peer support in UK policy. This will be explored in the followed discussion chapter.

5.4.2 Shared experiences

Peer support is commonly described as those with shared experience supporting each other. However, several interesting findings also emerged when participants were asked what their idea of a peer was, and what the characteristics were of the individuals with whom they found it the easiest to connect. Generally, participants

said that it was important to have a shared experience of a similar form of mental distress and defined this according to classifications such as depression, anxiety, hearing voices:

'I have thought about this as well, who are my peers, I wouldn't understand, I'd accept obviously, but I wouldn't understand the experience of an eating disorder or hearing voices' (Interview 11).

This was particularly important for face to face peer support groups and was evident from the way in which some of the face to face groups had quite actively curated their membership around specific definitions of mental or emotional distress:

'I think it's important that we've only had the group open to people who have depression, or depression with anxiety, so not anxiety disorder on its own. We have had problems because we have had people with schizophrenia who are also depressed so we make it quite clear, because we've found we can't support people with schizophrenia. We can't support people whose main problem is substance abuse although we do have people who use alcohol and drugs to cope and as long as they're not disruptive, we're accommodating, but we find that by having that quite narrow focus that that gives people a lot in common' (Interview 2).

Where groups were less condition specific, this was not always helpful for participants:

'Often people say 'there's this service', you know, different support groups, like Mind, which I actually went to one, but a lot of the people were very ill, and they weren't just depressed, some of them had schizophrenia, and I just didn't feel it was for me' (Interview 3).

However, within this definition many participants found the experience of mental distress very unifying in face to face peer support groups, regardless of the background of individuals:

‘We come from different backgrounds ... but we find a shared experience of depression quite unifying’ (Interview 2).

‘I think just the commonality of having had depression is enough to link me to somebody. If they’re male and young, or female and old, it doesn’t seem to make much difference. The experience of depression is what links us all together’ (Interview 3).

‘Well it’s very unifying because we all have a similar sort of experience’ (Interview 7).

Two participants had a slightly more specific idea of peer, based on their respective lived experiences of having been in psychiatric hospital and working in a mental health setting. For the former, it was suggested that it was the shared experience of mental or emotional distress that served as a starting point to build trust and connection:

‘In terms of peers and who I find it easy to talk to, I mean most of my close friends have been in psychiatric hospital, and that helps, so I think, I tend to share, I tend to build a bond from a point of things not being very good for me, or for the other, or for both of us, and I think that’s the way to build trust so that’s kind of where I make connections I think’ (Interview 12).

‘Actually, who I consider to be a peer are people with lived experience who also work in mental health, that’s the category that is the biggest kind of peer group in my mind’ (Interview 13).

Some online platforms, such as Instagram allowed participants to filter more extensively who they engaged with. One participant described how this had had the result of reducing the diversity of the people she engaged with online. Conversely, she felt that engaging with a wider demographic of people in a face to face peer support group had pushed her out of her comfort zone, and that this had been helpful:

‘On Instagram or on WhatsApp, you filter everything. So, you are not actually being exposed to people who are different to you but have a similar experience ... I don’t interact with as many diverse people on Instagram, at all ... If you have a group and you don’t know who’s going to walk in, you’re going to be exposed to people who are much more diverse, which I think is really really healthy and helpful, and you make connections with people’
(Interview 8)

Whilst being pushed to engage with people from different backgrounds was not mentioned explicitly by other participants, others did mention more generally the benefits of having face to face group members from a diversity of backgrounds and the equalising nature of the face to face peer support environment:

‘And when we’ve started groups that are very small, it was like everyone was a peer, regardless of their background. So, they might be a doctor, or they might be someone who never gets out of a council flat, and it doesn’t matter. Everybody’s got the same right to express their experiences. It is one of those odd places where people cross class, cross ethnicity and everything’
(Interview 1).

The need to connect with those with very similar lived experience online was not as explicit as in a face to face group, perhaps because individuals were looking for a different kind of support. However, one participant did reflect that she did not find online groups which were open to all forms of mental or emotional distress that helpful, because she couldn’t relate to the experiences of others sharing through the group:

‘And there’s another group, it’s a Facebook group, called [name of Facebook Group], which I’ve started to look at but it tends to be people with different problems, it’s not just depression, I think a lot of them have got personality disorders and they’re often, what they post on the site, is they’re moaning about the treatment they’re getting, and being quite negative and even talking about wanting to kill themselves, so I tend not to look on there when I’m depressed’ (Interview 3).

As discussed, the majority of one to one informal peer relationships that individuals formed came from attending face to face peer support groups or in mental health services. As such, these peers generally also shared an experience of mental or emotional distress in the same way as face to face peer support groups. However, a few participants had developed close relationships with peers with slightly different experiences of mental or emotional distress, and emphasised the importance of connecting with people over very similar lived experience:

'It may not be necessarily someone having similar experiences, it may just be somebody you can get on with. So I have made several friends through the groups, and you know, for example, one person has experience of psychosis which I don't have, and she's in hospital at the moment so she's on my mind. I think it was the fact we could talk in an intelligent way. I think different people have different styles and some people find it much easier to talk about feelings ... it's also interesting that several of the other people I've got to know, have also gone through a diagnosis of autism, and I didn't necessarily connect with them. In a couple of cases I did' (Interview 1).

5.4.3 Peer and non-peer friendships

The majority of participants referred to their one to one informal peer support relationships as friends. One participant particularly enjoyed thinking about his peer friendships as a unique form of one to one peer support in the interview:

'Okay, so basically, Jack and Terry, Jack is quite old school so his peer support work is more based on understanding, listening, being, he's very empathetic, quiet, laid back and relaxing to be with and really astute observations at important times from his experience, and then the difference between that, Terry, Terry's younger, he's sparky, he fights his voices, he's into having a good time, playing computer games, cheering yourself up, and not being too worried, if you have OCD, yesterday was worse than today, so he's more in the moment. Yeah so, that's the sort of difference. I think that Jack gives me more insight into my condition, whereas Terry is good for my self-esteem. I suppose for both of us, me, Jack and Terry, I see our journeys as trying to fix ourselves, and we're kind of happy, I don't know how that

works, but ... the one to one, I like this phrase one to one peer support!
Yeah, it's really cool' (Interview 14 – names changed).

Whilst not all participants had a strong network of non-peer friends, those that did described the difference in the support they were given by peer and non-peer friends. Non-peer friends were identified to be important offering emotional support but not support directly related to experiences of emotional or mental distress.

'It would be different in that probably they wouldn't quite exactly know what you're going through so probably you'd go through slightly different things, so if I had a symptom of depression, if I had a problem that I wouldn't have thought the average person, or a friend or whatever, would understand, I would probably go to somebody who's been through it. But if it's a more general problem, something perhaps that could lead to depression, I don't know, a bad situation in your life, for whatever reason' (Interview 5).

'Okay, so with my best friend, Jim, he doesn't have any experience himself of mental health, it's interesting over the last month, his mum's become mentally unwell, so that's difficult for him but basically Jim has normal words for my experiences, so if I'm hearing voices, he'll touch me on the arm and say 'are you okay, name', and I'd say yeah. I'm a bit stressed out, he'll say 'don't worry, you've chosen a tough one this time, I'm here for you, call me any time, let's hook up next week and we'll go for a bite to eat' (Interview 14 – names changed.)

The importance of one to one informal or peer friendships in supporting individuals to process and conceptualise their experiences of mental or emotional distress are explored in the following section.

5.4.4 Terminological complexities

In the interviews, one participant suggested that the term peer support was still unfamiliar to many people:

'I'm familiar with it, I don't think it's very helpful because most people don't know what peer means' (Interview 13).

This was something that I myself experienced when I attended groups to talk about my research:

Research Journal Entry July 2019:

'I attended a London based peer support group around depression today to ask if any of the members would like to take part in my research. I was really struck by the unfamiliarity of the term 'peer support'. Some were familiar with it, but others clearly didn't understand its meaning. I found I was doing a lot of explaining that it meant support from others with similar lived experience'

I also noticed that several participants preferred the term 'self-help', these were most commonly those who were connected to a face to face peer support group which had originally been set up 30 – 40 years ago.

'I tend to use the term self-help...I think of it as a self-help group but I suppose it means the same thing' (Interview 3).

'Well, I always think of mutual support groups or self-help groups, that's what we used to call ourselves, self-help groups, and [National Support Organisation for Depression] is a self-help organisation, it always was, right when it was [National Support Organisation for Depression], encouraging that' (Interview 11).

Finally, one participant described how recently peer support had become a term which was widely used:

'I didn't hear about it until probably about 10 years ago. And then ten years ago, attending [groups], I started to hear, I mean it was quite a buzzy word, people were like 'what is peer support?' (Interview 14).

The importance of labelling and terminology when we come to peer support will be explored in the following discussion chapter.

5.5 Contribution of different forms of peer support to individual well-being

Thematic analysis of the interview data revealed four important ways in which different forms of peer support contributed to individual well-being. Three of these, I consider to be 'transformative' as they relate to significantly changing the circumstances or perspective of individuals. These were 1) the reframing of experiences, leading to self-acceptance, 2) the development of new forms of social support and 3) reciprocal giving, leading to increased self-esteem.

Different forms of peer support also played an important role in supporting individuals to develop coping strategies and maintain their day to day well-being. Whilst this can still be considered very important for individual recovery, it does not necessarily move someone on in their recovery in the potentially profound manner as the more transformational ways described above, because it does not significantly change how they think about their experiences, themselves or their life circumstances. The following section explores the unique contribution of different forms of peer support to each of these themes.

5.5.1 Reframing and self-acceptance

One of the most prominent themes that emerged from the interviews was the unique way in which different forms of peer support had enabled individuals to process, conceptualise and understand their experiences of mental or emotional distress. Participants described five different processes which facilitated this: 1) listening to the stories of others enabling them to move away from feelings of self-blame, 2) constructive confrontation from peers creating new senses of personal responsibility, 3) in-depth exploration of feelings, enabling new personal insight, 4) increased awareness of both the struggles and successes of others leading to increased feelings of gratitude and reflection and 5) the identification of role models, facilitating feelings of hope.

These reflexive processes were not equally shared across all forms of peer support. Face to face group peer support offered the greatest diversity in hearing from peers from a wide range of backgrounds and a safe environment to process and challenge existing perceptions. Face to face peer support groups also provided access to peer

role models and created the strongest sense of awareness of the struggles of others. However, it was one to one informal peer support that offered participants the opportunity to process and explore their feelings in depth in a way which was not possible in a face to face group setting or online. Finally, whilst both online support and face to face groups played a role in creating an increased awareness of the struggles of others, the transient nature of relationships online meant that this awareness was more superficial.

Processing by listening to the stories of others

Several participants described how initially, they didn't really understand their experiences of mental or emotional distress, but that through listening to the stories of others in face to face peer support groups, they had been able to develop an understanding of what they had experienced. Importantly for their individual well-being, it also enabled them to reframe their experiences as something for which they were not personally responsible, and that their experience of mental or emotional distress was not a result of a personal weakness:

'Three years ago or something, when I was getting better, I felt I understood the depression, but the depth of it, it's so much deeper than you can imagine, which has taught me a lot, when I go through what other people hear, when they talk about it, then I got so many examples, you know. That's why I used to like listening to other people. It gives me more, it gives me more, I don't know, more examples' (Interview 4).

And I can see it then as an illness, it's not my fault. It's not that I'm thinking wrong, you know, I've actually got an illness and my brain isn't functioning properly when I'm like this' (Interview 3).

In addition to reducing a sense of self-blame for their experiences of mental or emotional distress, participants suggested that hearing the stories of others enabled them to feel less confused and validated in their own experiences. This led to a sense of personal acceptance, facilitated by the acceptance of others:

'It's a bit hard to describe exactly what it is but there was also, usually, what we aimed at, was this sense of acceptance. That, really, I suppose, it wasn't your fault. That was one of the most important things, there's a lot in depression, and probably anxiety as well, of what I would call feeling bad about feeling bad, and it's like 'why am I this way when other people are worse off than I am?' and that's reinforced by what people say around you when they are supposedly trying to help. But I think if someone actually says, well, that is how you feel and I can kind of understand it, yes, that's comforting and clarifying' (Interview 1).

Two participants also shared how attending face to face peer support groups had enabled them to develop new conceptualisations of the societal pressures and structures that can contribute to individual mental or emotional distress:

'What I really began to cotton on to and I really began to feel a connection was when people talked about their feelings about the world, and how it might be a problem with the world, and not be a problem with them.... all sorts of alienating things about competition and lack of cooperation, lack of consideration for others and it began to make sense why people are depressed, from what they've been through. And people would talk about their past as well and it was quite clear that it wasn't so much talking about those things that helped them to get over it exactly but it helped other people understand and I think that was the main thing that I was missing, that I began to get more of, more understanding' (Interview 1).

'I think I have discovered the solution for mental health and the way I put it is the system, that make us ill, the social pressure' (Interview 16).

Again, this re-framing served to move away from ideas of experiences of mental or emotional distress as being a result of a problem with an individual, but instead drew attention to the wider circumstances in which individuals might be experiencing distress. It is of interest that participants came to a number of different understandings about their experiences, with some finding solace in the idea that their experiences of mental or emotional distress were an illness, and others finding it helpful to locate the origins of their experiences of distress externally to

themselves, as natural responses to unhelpful social structures. This suggests the flexibility that peer support offers individuals when trying to conceptualise and process their experiences, beyond the bio-medical model.

Challenging existing perceptions and developing a personal sense of recovery

Face to face peer support groups were also described to be unique in the way they facilitated constructive challenge from others. This is illustrated by the description one participant gave of how confrontation from another group member was pivotal in shifting her thinking about how she treated herself:

‘Peer support, to answer the first part, contributed to my well-being because it was confrontational, the defining moment ... somebody stopped me mid-sentence, and said, you would never say that to someone else, you would never talk to someone else the way you’re talking to yourself. And I was like ‘whoa’, that’s actually really true, and to this day, when I think about it, I kind of get shivers, because that for me was like ‘oh” (Interview 8).

Others also talked about how attending a face to face peer support group enabled a re-balancing of views and developing a sense of personal sense of responsibility with regards to their recovery:

‘It’s difficult when I’ve had a difficult experience under psychiatry to be more accepting of people’s views of finding a value in it ... [going to the group] ... helped me to get some balance’ (Interview 12).

‘I realised how important self-responsibility is, that self-responsibility is healthy and it’s my decisions that guide me into my health’ (Interview 16).

These reflections show how face to face peer support groups offer an opportunity to challenge existing perceptions in a way which is constructive and helpful for participants, enabling them to shift their thinking and develop new senses of personal responsibility.

In-depth explorations leading to new understanding

Informal one to one peer support relationships were identified to play a different role to face to face groups in how they supported participants to conceptualise their experiences. Such peer relationships were described as playing a very significant role in enabling participants to process their experiences in depth, by talking them through on a one to one basis. This was unique to one to one informal peer support and illustrates the way in which peers tailored their support towards each other, depending on what was needed:

‘It was in the one to one with Sally, because she knew something was happening, because she was very intuitive, that I was able to talk in depth, cos she encouraged me, so that is a point that some people will not be able to talk about certain things within a group. You know, they need that one to one’ (Interview 11 - name changed).

‘The peer support I’ve had from Jack is priceless, you never really get an answer, but you get a way to think about it’ (Interview 14 – name changed)

One participant also described how sharing with a peer on an informal one to one basis felt less risky than in a group setting:

‘There’s less risk, I suppose with a friend, if I explore things, it’s interesting’ (Interview 12).

This unique offer of informal one to one support offers some explanation as to why participants found it helpful to blend different forms of peer support together to enhance their well-being. Attending groups offered participants the opportunity to hear from a wide number of perspectives and the one to one informal relationships they developed, either through attending groups or meeting through mental health services, offered spaces to explore and process their feelings in more depth. This echoes the way in which some participants also used therapy alongside attending face to face peer support groups, in order to have more space to reflect and process their experiences.

Increased awareness of the experience of others leading to gratitude and reflection

As participants engaged with peers with similar experiences of mental or emotional distress, they were able to reposition themselves and their experiences. Peer interactions led participants to build a greater awareness of the challenges faced by others and, for some participants, this created a sense of gratitude and reflection which contributed to their own sense of well-being. Understanding more about the experiences of others with mental or emotional distress was facilitated across all forms of peer support, although it was suggested that the increased intensity of relationships in a face to face setting, when compared to online, did mean that participants developed more detailed understandings of the challenges faced by others in this setting.

Online support offered a quick way for participants to reach out at times of distress and to be reminded that others were also struggling:

‘Only when I’m depressed, I wouldn’t really look at it if I’m not depressed. I suppose it’s when I’m very low and I’m very isolated, and I just want to know that there are other people out there feeling like I do’ (Interview 3 – talking about an online forum).

A few participants also described how meeting peers informally, whilst accessing inpatient mental health services also served to normalise their experiences and create new perspectives on the situation of others:

‘There was also just the support of knowing other people were doing similar things around you ... It’s just that sense of kind of just normalising the experience, normalising the treatment’ (Interview 13).

Several participants also described how attending a face to face peer support group offered opportunities for reflection about their experiences in the context of the challenges that were also faced by others:

‘Well, the knowledge of knowing that there are other people walking around who are feeling similar to you, cos you tend to think nobody is, I don’t know

why you think that but when you go into the office, when someone asks how you are feeling, you don't say 'oh I feel a bit suicidal' actually, you just wouldn't, and you don't. So, you know the knowledge that other people are feeling exactly the same, that you're not just hypersensitive and being daft, that you're not, that other people are experiencing things in the same way' (Interview 6).

'And you know, knowing that other people are going through it, and you know, people who are in a much worse position than me, so people who are financially strapped for cash and have to work, or sort of living in not very good conditions and who are actually very lonely' (Interview 3).

'There are some people in the group... they've got it worse than me' (Interview 15).

Across all forms of peer support, opportunities to hear about the experiences of others meant not only that participants felt less alone, but offered new comparisons which enabled them to reflect on, and reposition their understanding of their own experiences.

Identifying role-models and developing a sense of hope

Participants also mentioned a further benefit they had experienced from comparing themselves to others, in the form of role-modelling. Coming into contact with others who were further along in their recovery journey instilled participants with feelings of hope and a sense that they too would be able to recover or cope:

'It really helped because I hear voices and stuff like that, really helped with my experience, knowing that someone has been through it, and he was an older chap and he says he still struggles with it but he can cope and that was great, you know, I hadn't met anyone who'd been through it' (Interview 14 – talking about the experience of a face to face peer support group).

'When I first went into hospital and I saw other people with similar diagnoses and I saw them being able to do things for the first time, and it's like, I don't

think I would have believed I'd have done it but other people were doing it, so perhaps I can do it as well' (Interview 13).

Offering individuals opportunities to develop greater awareness, both in the challenges faced by others and of individuals who have successfully navigated their recovery journey, were an important feature of how peer support facilitated new social comparisons with others. All forms of peer support enabled individuals to reposition themselves and consider their experiences in a new light, although online support did not seem to offer the same opportunities to identify role-models as face to face settings.

5.5.2 Development of new forms of social support

As discussed at the beginning of this chapter, participants had often chosen to engage with peer support because of feelings of stigma and isolation. However, it became evident in the interviews that the way in which different forms of peer support complemented or enhanced other forms of social support was very complex, with each form of peer support offering something different to participants. Face to face peer support groups played a particular role in creating spaces of belonging and enabling participants to develop their social skills. For some peers, this had led to them connecting with the wider peer support movement, finding this helped them develop an additional sense of purpose. Informal one to one peer support relationships often became the foundation of a new social support network for individuals who previously had found it difficult to connect with others. However, this meant that some individuals felt themselves to live in 'a mental health bubble', and wishing to connect more widely with those without direct lived experience of mental or emotional distress. Finally, online support was described to be particularly helpful for those who wished to connect but felt they were unable to do so face to face because of social anxiety.

New spaces of belonging and developing social skills

Face to face peer support groups were identified to be particularly helpful in providing a physical space where participants were able to spend time with a group of people where they felt they truly belonged:

'It helps me if I'm with other people, other members of my tribe'
(Interview 3).

'It makes you feel you belong, it's a group of people and you're not on the outside, you're not completely on your own, you belong to, there are other people who have similar experiences, the strength, I keep reiterating, but that's the powerfulness of it' (Interview 6).

Several participants also said that attending a face to face peer support group had enabled them to develop social skills and to relate better to others. One participant described attending a face to face peer support group as a 'stepping stone' to the wider world:

'I'd also say one big thing, having mentioned autism but this was also very clear to me going back to the 90's, is that there are some people who are very isolated and lack a lot of social skills and I think I was in that category. And actually, dealing with difficult emotions, you're not very confident, but when you see it in a group of people without the fraught atmosphere of the family, you begin to ... it's a bit out of your comfort zone initially, but then you become more comfortable with meeting people from different backgrounds... in some cases, including mine ... going to a self-help group is kind of a stepping stone to social connection with the real world' (interview 1).

This was evidenced by the way in which, for some individuals, attending face to face peer support groups had also led to them engaging with the wider peer support movement. This also contributed to new world views and enabled individuals to feel part of something bigger. Several participants described how access to the wider peer support community gave them a sense of well-being:

'Once you get involved in one thing, you hear about more things, and they'd mainly be campaigning projects of organisations ... it was very much being part of a community. It's all part of my identity' (Interview 11).

‘... if you’re looking at well-being, the principles of action for happiness and great dreams is one of the keys of that... feeling that you are part of something bigger, that you can’t necessarily articulate, but it’s that movement, it’s that feeling’ (Interview 9).

‘It’s opened up a new world, given me an alternative paradigm within which to live ... all I’ve gone through, it’s not for nothing and it can be used to help other people going through similar things’ (Interview 14).

Face to face peer support groups also seemed to be unique in the way they helped participants to develop a number of social skills such as relating to others, extending compassion and listening:

‘I feel I’m much better at negotiating different situations. I find it easier to extend compassion to people. I find it easier to accept compassion, accept compliments, accept that I’m not exceptional, uhm, so sorry, skills, so some of this comes about from facilitating groups as well’ (Interview 1).

‘I have learnt to deal with my life, deal with people, relate with people and to myself because I have learnt to respect others. And that’s what I get from the groups as well’ (Interview 16).

‘Tactfulness, well people say I can be direct but sometimes people say they want something and I say no, because I don’t want to give them false hope. But the skills you learn more understanding of how it is for people, you find out what helps them, what not helps them and also not to judge everybody, you know, on what you see. Communication skills to be honest’ (Interview 4).

‘For me it’s quite inspirational, it’s good for me to train myself to listen’ (Interview 9).

These comments suggest the importance that face to face peer support groups can play in building confidence in engaging with the wider social world.

Building a wider social network

A number of participants started to engage with peer support at a time when they felt unable to connect with friends or family. Whilst many informal one to one 'peer friendships' were first formed as a result of attending peer support groups or accessing mental health services, it was as these relationships moved out of the group or service setting and became informal one to one relationships in their own right, that they contributed the most to building the overall social support networks that participants were able to draw on.

Several participants described how the majority of their social network was comprised of others with lived experience of mental or emotional distress:

'I feel a lot of my life, maybe half my friends are from this sort of thing'
(Interview 1).

'I haven't had that much meaningful contact with anyone who hadn't been through quite a lot of distress' (Interview 12).

One participant also described how she had actively curated her social network to include solely individuals who understood experiences of mental or emotional distress. She felt most comfortable with others who could bring understanding without explanations:

'I think I'm quite lucky, I live in a mental health bubble, I don't have to talk about my mental health to people who don't understand very much'
(Interview 13).

However, a couple of participants also described how they felt slightly conflicted by having social support networks which were dominated by friends with lived experience and expressed a desire to develop more friendships outside of the mental health bubble:

‘... in some ways I feel these groups have taken up enough of my week, or enough of my time and I feel I’m spending a lot of time with aspy, or depressed friends ... I wish in a way I could make a break from it. There is a social pressure, there is a bit of a stigma associated with it’ (Interview 1).

‘I think that’s a gap in a sense, which I’m perhaps ready to fill more, to get more into doing lighter things. I think there’s scope for that and in some ways maybe I have addressed that it isn’t just the case of having contact with people who’ve had a certain level of trauma or whatever, I suppose your question is just so central to feeling at one with the world really’ (Interview 12).

These reflections from participants demonstrate the important role that one to one informal peer friendships can play in the overall social support available to individuals with experiences of mental or emotional distress. Such relationships can end up forming a substantial part of the social network of individuals who have felt themselves to be isolated or stigmatised as a result of their mental or emotional distress. However, whilst such networks can offer protective bubbles of understanding, it is important to note the value that participants also attached to building connections with the wider world.

Connecting whilst experiencing social anxiety

Online peer support was seen to be particularly important for those who felt unable to attend a face to face peer support group because of social anxiety but who still wanted to connect. One participant, who also facilitated a face to face peer support group spoke of her experience of supporting two fellow members, both of whom experienced social anxiety, by email and on an online blog:

‘[a group member] attended a group but then he became unwell, very, very socially anxious and then didn’t come back. He had problems with other things in his life, you know. And he wanted to come back, he kept saying he would, but he couldn’t, you know, he became a recluse. But we maintained contact through email. And we have another young man in the group, who has a blog about his depression and it’s a closed blog, so people can be

invited, but he told us about it. He doesn't come often but several members, including myself, support him on the blog... I think methods other than face to face can be really helpful for people who have social anxiety' (Interview 2).

It is of interest that whilst peer support was provided by online means, it was connected to a face to face peer support group. These individuals had only come by this support network by first engaging with a face to face group and this demonstrates the overlaps that can exist between different forms of peer support. As this study focuses on the plurality of experience, I did not interview individuals who had only engaged with online peer support but the extent to which this is used by individuals in place of other forms of peer support for this reason would be an interesting area for further research.

Whilst online peer support still allows for a connection when face to face peer support is felt to be too much, one participant questioned whether having the option to connect online, and therefore not needing to connect in person, could actually facilitate avoidance of social contact, which ultimately could be unhelpful:

'...to some degree, the more diverse medias that we have to connect with the better, at the same time, if you're already feeling, if you're agoraphobic for example, and you can connect with people on Instagram, well, why would you leave the house? Why would you put yourself in an uncomfortable position if you can avoid it? That's not helpful necessarily for those very anxious moments'. (Interview 8).

Only two participants described strong social connections as a result of engaging with peers online. These were both older participants who used online peer support as part of their day to day routine; one through an online email correspondence with a peer and one through Facebook groups to connect with others. This study has highlighted the potential complexity around the types of new social relationships that could be formed online and more research into the conditions under which individuals with experience of mental or emotional distress form new lasting social connections online is needed.

5.5.3 Reciprocal giving and increased self-esteem

As explored in the conceptual chapters to this study, one of the unique ways in which peer relationships differ to professional relationships is that they also offer those receiving support the opportunity to help others. In this study, a large number of participants described how the reciprocal nature of peer support was important for their well-being because of the way it had helped them to build self-esteem and to feel useful. However, two important themes emerged when it came to patterns of reciprocity across different forms of peer support, and the implications of giving and receiving support in different ways for individual well-being.

Firstly, face to face peer support groups offered considerable flexibility over how much support individuals offered others, and often were marked by a unique pattern of participants giving more to others over time. Several participants described how they did not feel able to support others when first attending a group but found that their peer relationships became increasingly reciprocal as they gave more to others, with many ultimately taking on roles as facilitators of groups. A second important question relates to the balance of giving and receiving in different peer support environments. Several participants described a natural two-way equilibrium they had reached in their informal one to one peer support relationships. In this way, the giving and receiving of support was more equally distributed than in either face to face group or online environments. Online peer support seemed to be the least reciprocal, with participants generally describing one way interactions or more passive engagement where they might read comments on a forum but not choose to respond to the posts of others. However, even non-reciprocal forms of peer support, online, or receiving and reading peer newsletters, were identified as helpful to well-being, through enabling a sense of connection to others. This raises an important question over the role of reciprocity in enhancing individual well-being; the additional benefits offered by more reciprocal forms of peer support, and how non-reciprocal forms of peer support can still contribute to well-being.

Giving more over time

Many participants who attended face to face peer support groups mentioned the importance of being able to help others. One aspect that was unique to face to face

peer support groups were descriptions of serial reciprocity, where participants did not necessarily feel able to give back to others at the beginning of their engagement, but developed this over time:

‘When I first came, I didn’t have anything to give, I needed some support, now I feel better, healthier’ (Interview 6)

Being able to help others in this way was an important contributor to individual well-being because it led to participants feeling useful, knowledgeable, and built their self- esteem:

‘The other thing you get from peer support is actually, when it’s the other way round, when you’re listening to someone else’s problems, you’re helping them, and helping someone also helps you in a sense ...you’re doing something useful. And that’s actually very important, it’s a big thing’ (Interview 5).

‘You feel safe, among friends and useful’ (Interview 7).

One participant also described how receiving positive feedback from others that her experience and insight was valuable improved her self-esteem:

‘To actually realise I am the person who really understands the crisis teams ... it became a sense of self-esteem for me, you know, I know things’ (Interview 13).

Many participants had taken on roles as facilitators of face to face peer support groups. This provided further ways to help peers and provided individuals with a sense of purpose. Participants clearly took their responsibility towards other group members very seriously, and found their new roles rewarding:

‘It’s given me, being involved, has been a bit of a purpose’ (Interview 1).

'When you're a facilitator, there's lots of responsibility turning up early and then setting up... when I'm there, people turn up and I see it's worth it ... you do feel good' (Interview 4).

'I go out of my way to organise my life so I can go to the group... because no-one else was doing it, I did it on my own for 8.5 years ... you feel useful, I must admit, I do feel useful running the group. It's difficult for me to admit because I have an underlying sense that I'm worthless' (Interview 7).

'They always look to me to book it [group social activities], I'm the main man now' (Interview 15).

Interestingly, for one participant, the personal impact on well-being from helping others in face to face peer support groups were less conscious, and something they hadn't thought about before reflecting as part of the interview process itself:

'I used to be a nurse so a lot of my work was listening to people... I do feel I'm quite good at that. I actually hadn't thought of this before but being able to empathise and being good at what I do, gives me a boost' (Interview 3).

Balancing giving and receiving

Whilst face to face peer support groups offered participants multiple ways in which they were able to help others, these opportunities meant that some individuals were putting a lot of effort and energy into supporting others. This was not without its challenges, and the potential problems of facilitator fatigue and maintaining well-being whilst supporting others are discussed later in this chapter. One striking feature of the informal one to one peer support relationships described by participants was that they seemed to have achieved a good balance which was beneficial to the well-being of both peers. Many participants had found an equilibrium whereby the giving and receiving of support naturally shifted between peers:

‘At the moment it’s more of me giving Cath support because she’s really struggling at the moment with depression. And there was another member who was very supportive to me for a while, talking on the phone, and just going out and doing things, concerts together, things like that’ (Interview 2 – name changed).

Online, support transactions were less balanced, with two participants explicitly describing one-way interactions in which they were either giving or receiving support, but not both:

‘I think with the online groups, I don’t actively contribute. I’m more of an observer, uhm, and again it’s being able to read about other people, feeling like I do and not feeling so isolated or so scared by it’ (Interview 3).

‘I usually felt that I was the one not needing support but trying to help, that’s the way online groups tend to go for me’ (Interview 1).

One participant, who also facilitated a face to face group and had considerable experience of online peer support forums, talked of the difficulty he had experienced in encouraging others online who were ‘lurking’ and not contributing, to actively engage in peer support:

‘... online, I think there are people who lurk and don’t feel they are confident enough to express themselves, and it’s difficult to encourage them’ (Interview 1).

Despite the less reciprocal nature of online peer support relationships, participants still found them helpful as a way of connecting to others and knowing that there were other individuals also struggling with their experiences of mental or emotional distress. Sometimes, just reading about the experiences of others was cathartic. Several participants made very interesting observations about the importance of receiving newsletters from peers, and how just receiving something like this made them feel part of a community:

'Because the newsletter that Julie used to send out, every couple of months, you know, it would tell you what was going on, and I always remember she said, if, you know, if she was a bit late sending it out, people used to ring up and say 'have I fallen off your mailing list?'. Because people actually liked that regularity, every couple of months, I'm going to get a newsletter that's going to tell me what's going on. And it made people feel part of a community and they might never use any of the things that were advertised in the newsletter but they liked to know it was there' (Interview 13 – name changed.)

'...certainly, well I still use it as peer support, certainly in the old days, you see the newsletter is made up mainly of member's contributions, that's the central thing, it's a means of members, it's a member's newsletter so members write in about experiences, what helps, it could be anything, or perhaps a poem they've written' (Interview 11).

Definitions of peer support often include reciprocity as a key characteristic. However, some forms of peer support appear to facilitate more giving than others, with face to face groups offering the most variety of ways to support others and patterns of giving and receiving support seeming most balanced in informal one to one peer support relationships. Even passive engagement in forms of peer support, without giving back to others was of some benefit to participants. However, as being able to give to others was an important source of self-esteem, it is important to consider what might be lost if individuals only participate in more passive forms of peer support in which they are not able to give back to others.

5.5.4 Developing coping strategies and maintaining day to day well-being

In addition to the three potentially transformational themes discussed above, different forms of peer support also played an important role in developing coping strategies and supporting participants to maintain their well-being on a day to day basis.

The first way in which different forms of peer support helped participants to maintain their well-being on an ongoing basis was from the practical support and advice they

received. Participants described face to face peer support groups as a source of numerous forms of practical support such as information about benefits, coping strategies and access to materials, such as books. At times, support extended beyond the group setting. Conversely, one to one informal peer support was identified as providing participants with a unique form of tailored practical support. This was based on long-term relationships between peers, which enabled them to see, and to respond to accumulated patterns of behaviour. When it came to online peer support, a couple of participants described newsletters or blogs as a form of practical support.

The second important way in which peer support improved day to day well-being was by providing safe spaces where participants could speak openly about their experiences. This emerged most strongly in connection with face to face peer support groups, where having a physical space they could visit on a regular basis offered them a sense of routine and an ongoing safety-net. Participants also described how one to one informal peer relationships offered safe spaces where they could be themselves and not explain themselves. Here non-verbal communication and 'not having to explain yourself' became very important, as well as the freedom to speak openly about your experiences. Online peer support was not described as a safe space or a place of refuge in the same way as other forms of peer support and perhaps this can be partly attributed to the fears that are referenced earlier in this chapter (Section 5.3.4) towards 'faceless' mediums.

Practical support

The first way in which different forms of peer support helped participants to maintain their well-being on an ongoing basis was from the practical support and advice they received. Around a third of participants identified several different forms of practical support that they had been able to access by attending a face to face peer support group. This included support with benefit applications and appeals, ideas for new coping strategies and access to materials such as books on depression. Practical support sometimes extended beyond the face to face peer group setting with hospital visits or additional practical support with benefit applications given outside of the group.

One participant stressed the frequency with which welfare benefits arose as a topic of conversation within the face to face peer support group he attended (and facilitated):

‘Welfare benefits ... it’s a frequent topic of conversation. Almost everyone in the group is having to reply on DLA or PIP as it’s now called, some of them have been translated from DLA to PIP and some haven’t. I regularly contact the [Location] Benefits Adviser. I give his phone number to members of the group’ (Interview 7).

Others talked about how discussing different coping strategies had encouraged them to try new things and how hearing from others in the group with direct experience of these coping strategies made the suggestions more helpful:

‘... a lot of it is about sharing ideas or I find this helpful and it’s good to know that some people find exercise helpful, and some people find volunteering helpful and they’ve actually done it and it’s worked for them, it’s more than just a random piece of advice’ (Interview 1).

‘I think so, interaction with people, picking up coping techniques, so for example we have colouring books there, and before I went there I never really was into colouring, but these days I do colouring, so people talk about coping strategies, so I say ‘this is what I do’ and they say ‘this is what I do’, and I think ‘oh I could try that one’. So you learn from each other’ (Interview 4).

A few participants also mentioned that it had been helpful to be able to access new materials through attending a face to face peer support group, including books on forms of mental or emotional distress:

‘They also had a lot of books that you could borrow, books on depression which was good, so books that I hadn’t heard of’ (Interview 3).

Practical support also extended beyond the face to face peer support group meetings themselves. This participant, who also facilitated a face to face group

reflected on how practical support beyond meetings included hospital visits and support with benefit appeals:

‘People do support each other in different ways, Other things we’ve done, we had one gentleman who ended up in hospital, partly because of his mental health problems, and self-neglect, and four of us went to visit him and another member ... helped him with his benefit forms, went with him to his appeal ...so yes, that’s a different kind of help, that’s more practical’ (Interview 2).

One to one informal peer support also provided practical support but in a different way. Here, peers tailored their support to the particular circumstance of their ‘peer friend’. One participant mentioned a peer who always called at a particular time of day because she knew that would be when her depression was not as bad and she would be able to speak:

‘So one particular friend of mine, she phones, I’m depressed at the moment, you can probably tell, she actually phoned me yesterday because, my depression takes the form, I’m really bad in the mornings, and then it gets better as the day goes on, and around 6 o’clock, my mood really lifts, so she phoned me at six and she said ‘Oh, I know you wouldn’t have wanted to talk before this, and I just wanted to say hello, how are you?’ (Interview 3).

Another participant talked of the accumulated knowledge that developed in a one to one peer support relationship and how they led to being able to ‘see the patterns’ of behaviour:

‘After a while when you know them for a few years, you can be more direct, which is useful, because you start to see the patterns, what the person does’ (Interview 4).

Finally, one participant talked explicitly about the benefits of the longevity of the one to one peer support relationship and how that had enabled him to embed/ build up support over time, specifically with relation to developing coping strategies for specific situations:

'The difference is I think depth, maybe not depth but how personal it is, because the hearing voices groups, they would not necessarily, they would go round and say for example, if I'd turned up to a group and said 'my voices are terrible today because I'm worried about the police', and the facilitator might say, 'has anyone got any experience of that? Or can anyone help out'? And someone might pipe up and say, 'oh yeah, that happens to me too, or it used to happen to me and this is how I dealt with it', but if I'm still sometimes worried about it, that kind of thing, but the next week in the group, if it was a different group, we wouldn't then talk about it again but the difference is that they might have some really key ideas that would be introduced in the group, probably a bit more effectively than what I would say to Jack, week by week, day by day. So, it's almost like a sort of, because I see Jack every week. Do you see what I'm saying? So, I'm able to go through it more often, whereas the groups would probably only go through it once or twice at most. It would be a bit more grounded in a trained person's method of dealing with that, which overall might be more helpful, but then what I would say is that I would take that, what they are saying and reiterate it to Jack at the time' (Interview 14 – names changed).

A couple of participants described finding practical support from online peer newsletters or blogs. This was in the form of tips on services or explanations of how others had coped with their experiences of distress:

'It was mainly news about the organisation ... then news on what's happened, so for example, the trust is changing its crisis team number or older people's services are moving. And then stuff like, there's this article I came across on lavender oil or something' (Interview 13 – talking about an electronic peer newsletter).

'I sign up to people's newsletters ... and then I follow up the links, you know, I go from reading about people's experience of all sorts of things' (Interview 14).

Interestingly, participants in this study did not talk about asking specific questions or making requests for specific advice to peers in online forums. This may be because

so many were already able to access practical support in face to face peer support groups.

Safe spaces

Another important aspect of maintaining well-being on a day to day basis was for participants to have access to 'safe spaces' where they could express themselves freely or just be themselves. A number of participants described the importance of face to face peer support groups as physical spaces they could access on a regular basis. A few participants also identified time spent in one to one informal relationships as a space where they didn't need to worry about seeming 'normal'. However, rather than the freedom of expression identified as important in a face to face group, it was often also not having to talk or explain yourself that was important with a one to one peer. Participants did not describe their online experiences in the same way as other forms of peer support, as a refuge or safe space where they could relax. This may go some way to explain why face to face peer support groups, and one to one informal peer relationships to a lesser extent, played a greater role as an 'ongoing safety net' which enabled them to maintain their well-being.

Several participants described how being able to attend a face to face peer support group on a regular basis gave them structure and routine that was important for their well-being. Having a reason to get out of the house and a regular commitment was part of the way they managed their well-being on an ongoing basis:

'... I think it's a place to go. Even nowadays, it can be tough to make the effort to go there, if you're not feeling too good but somehow it still helps, it's something to do, it keeps me active and stuff, so it gets me out, it gives me a routine. It's a bit of a lonely feeling that you don't get now that it's in your life' (Interview 4).

'It gives me a focus, somewhere to go' (Interview 13).

However, beyond providing a physical space and a reason to leave the house, participants also described how face to face peer support groups, also created a space where you could be honest and speak freely, without fear of judgement:

'The group? Gets you out of the house, that's one good thing, if you're feeling a bit under the weather, often a bit anxious, with the voices and that, you can talk to people about it, and they'll listen, they'll listen to you, then they'll explain about their voices and what they've been through' (Interview 15).

The structure and routine offered by face to face peer support groups and the ability to access such safe spaces regularly, may explain why several participants seemed to feel that face to face groups were particularly significant as a form of peer support that provided a 'safety net' or 'insurance policy' that helped them manage their well-being. When asked what had sustained such long periods of involvement with face to face peer support groups, participants suggested that long term participation was needed because of the long-term reality of living with mental or emotional distress:

'The groups tell me that this is a very varied experience and usually a long - term issue that needs long term peer support' (Interview 7).

'But the thing you realise, with anxiety and depression is that it's cyclical, so it's very likely to come back, and you're just looking at ways of managing it' (Interview 6).

Face to face peer support groups were able to offer an ongoing reassurance or safety net to individuals which helped them to cope with their distress on an ongoing basis:

'I also say that coming to the group can be a way to help you not to relapse' (Interview 2).

'I think we can't necessarily solve the depression, and I still worry about dipping back into it but I think self-help groups have done more than most medical help. Firstly, I don't think I'm going to plunge down as far and I'll feel more authentic and less confused about the experiences I'm going through' (Interview 1)

‘Sometimes I wish I had the answer of what would help but there isn’t, it’s a day to day battle, we just have to carry on day to day’ (Interview 4).

Creating safe spaces in a face to face peer group setting was complex. Participants talked about the importance of being able to see others, confidentiality and group facilitation. Firstly, a number of participants suggested that it was easier for them to communicate fully with peers when you could see them. This allowed participants to pick up on the intricacies and meaning that others wanted to communicate, and overall led to a more ‘honest’ experience:

‘No, I more enjoyed face to face, because, yeah I enjoyed more face to face rather than text because sometimes you can’t see stuff, you write something, it can appear to be opposite meaning, it loses the meaning, you know’ (Interview 4).

‘I think there’s something about being able to pick up on the intricacies or detail in somebody’s human interaction’ (Interview 8).

‘The experience with [a face to face peer support group] is much more complete, online is a bit clinical, a bit, I can’t think of quite the right word, unemotional, it was good to have something rather than having nothing but with the (face to face) group, I don’t suppose it’s any different from any other group, maybe alcoholics or gamblers, you know for me, you are able to be totally honest, and just get the understanding and you get empathy, sympathy and you’re not being judged, you’re not being misunderstood, and people aren’t saying ‘Oh dear’ and not knowing what you’re talking about, never knowing or having experienced it’ (Interview 6).

Secondly, the importance of confidentiality in the face to face group setting was expressed by around a quarter of participants:

‘Anything said in the group stays in the group’ (Interview 15).

‘I used to have difficulties with confidentiality. But now I realise I don’t care. It is mentioned everywhere confidentiality but I have found a couple of times that people haven’t kept their confidentiality’ (Interview 16).

Different levels of facilitation across the three forms of peer support appear to have quite significant influence on both the content and format of peer support discussions and to contribute to creating a safe space. Two participants, who both had attended and facilitated face to face peer support groups for over 20 years talked in detail about their efforts to curate and focus discussion in certain ways, with both touching on the importance of ensuring that one person did not dominate the group discussion:

‘Well, peer support has to be well managed and facilitated because if the groups are not well managed, you can let somebody take over, who talks far too much about how bad they are feeling and how they want to finish their lives and how they intend to do it. That is not helpful, and that is not the place to be doing that. Or someone how just dominates, and you need someone there, we have ground rules that we read and I always say to people ‘please don’t be offended, I might have to cut you short to give everybody a chance’ (Interview 2).

‘I think what most groups have been doing for 25 years is having a round so that people get a few minutes at the beginning when they can say what’s on their mind. That sort of establishes a baseline level of equality, I suppose’ (Interview 1).

To a lesser extent, informal one to one peer relationships also played a role as a safe space. However, this was different in that it did not rely on a physical space, or a routine of attending or engaging at particular times. Earlier in this section, I talked about how participants sometimes found it easier to discuss their experiences in a one to one peer relationship because it was seen to be ‘less risky’ than speaking in front of a whole room of people. I have also outlined the gradual way in which these relationships have emerged over time and how well one to one peers came to know each other, enabling them to offer each other tailored support. The trust in these informal one to one peer relationships meant that peers could spend time together

and choose not to speak or to share their difficulties, as needed. There was no need to 'seem normal'. As such, these relationships can also be considered to offer a safe space for individuals experiencing mental or emotional distress, but in a different way to the face to face peer group setting:

'And uhm, you know she can talk about her problems, it's interesting because our depression often doesn't coincide, so if one's alright and the other one's depressed, we sort of, support each other like that and we go out together. You know, the other week, I went to the cinema with her and it felt alright to be with her, I didn't have to keep up a conversation, and if I was a bit quiet, I didn't feel bad about not seeming normal' (Interview 3).

'... going for a coffee, or just walking through town, I think, there's no boundaries, there's no ears, there's no eyes, you're on leave, you're walking through the town, you've earned your leave, so if you've had a shitty 24 hours, or a shitty week, or a shitty month, or a shitty family visit, or you've lost your leave, or had your leave decreased, do you know what I mean, I think you open up to that person, because they're not going to go and report back. And again, it brings me back to that point about trust. It's because I trusted that individual' (Interview 17 – talking about informal one to one relationships she developed whilst accessing inpatient mental health services).

For one participant, it was the combination of accessing face to face peer support groups and informal one to one peer support relationships that created a network of 'understanding' spaces:

'...it feels like something's freeing a little in me, it's a positive experience, and so, I guess, through all those groups and one to one, I've been able to do that more... the fear of how the status quo, doesn't go away but perhaps it subsides, and the feeling of having a bit of a network, where there are understanding places, that's pretty crucial I guess' (Interview 12).

The findings in this section identify how different forms of peer support can create safe spaces in different ways. However, it is important to note that participants did

not identify online peer support as a safe space in the same way they spoke about face to face group or informal one to one peer support. This may be linked to the barriers identified in section two, of engaging with 'faceless mediums' and what might happen to personal data shared on online platforms. One participant described explicitly how the faceless nature of some online forums had made it difficult for her to engage:

'Yeah, so I have found forums not helpful, but I think if it was more of a video, if I could see the person, but just typing, it gets it out of your head for five seconds, it sort of lets it out of you to a certain degree, when you're typing away, but then you can feel a bit silly, you're talking to nobody, so I think if you can see people and identify with other people's experiences' (Interview 17 – talking about online peer support forums).

There is huge diversity in the forms of online peer support available. These findings point to some features that might help individuals to feel safer sharing in an online peer support environment.

5.6 How different forms of peer support challenge individual well-being

This final section considers three themes that emerged around how different forms of peer support could in fact serve to detract from individual well-being. Firstly, how experiences of conflict, misunderstandings and distress play out across different forms of peer support. Secondly, challenges that emerge around maintaining boundaries when providing peer support and finally, the impact of funding problems, group closures and disruption.

5.6.1 Experiences of conflict, misunderstandings and distress

Several participants recognised the potential for conflict and misunderstandings across all forms of peer support and that these could lead to individual distress. However, participants also suggested that conflict in a one to one informal peer relationship, or a face to face peer support group was a relatively rare event. Conflicts on and off-line were resolved in different ways. Most commonly, if a participant had experienced conflict or distress whilst accessing online support, for

example a difference in opinion or receiving abuse from others, they tended to just shut down their engagement. In face to face groups, more opportunities existed to work through conflict, underpinned by the commitment made by group participants to be in a physical space together. Follow-up, for example running after an upset group member who had left a meeting, was also possible in a way which was not facilitated by online mediums. Only a few examples of conflict in a one to one informal relationship were mentioned and it was suggested that in situations such as these, participants would call on alternative support, for example speaking to a therapist.

Accessing peer support, especially in face to face group formats, was recognised to put an emotional toll on participants, as they started to process their experiences of mental and emotional distress. A number of participants also talked about the impact of the suicide of a group member, recognised to have significant repercussions and potentially, feelings of failure. A couple of participants mentioned the difficulty of hearing peers talk about suicide intentions online. However, the distress caused by this seemed to be less than in the face to face group dynamic, potentially because of the looser association between online peers.

Conflict on and offline

An important distinction emerged when participants talked about the differences between conflict that took place in a face to face group setting and conflict that took place online, for example in an online forum or a group email exchange. In face to face peer support groups, conflicts could be caused by disagreements over how groups should be run or specific pieces of advice given by peers:

‘The groups weren’t smooth running, as in all groups, people had fights or quarrels, or perhaps they’d disagree over how the group should be run, or what they were there for’ (Interview 11).

‘I think the only problem with peer support is that peers want to help too much and maybe they don’t have the expertise to help ... just because you have an insight into your own condition doesn’t mean that you’re attuned to someone else’s experience ... I know for other people, they have times

when they have big breaches of understanding... they never go back' (Interview 14).

'...we've had a couple of issues in the group, some tension, now I've been fairly immune to it, I can sort of see, having been through it myself and understanding that people can sometimes get paranoid about things, I can see that where people have got upset might be coming from, because I've been there, but sometimes not everybody can see that. So, some people have taken it more sensitively than others' (Interview 5).

Online, conflict most commonly emerged as a result of misunderstandings. Several participants described how meaning was sometimes lost in non-verbal communication:

'You can be more challenging when you're face to face whereas online, it only ever gives you an essence of something that's a bit deeper underneath I think' (Interview 8).

One participant suggested that conflict online had escalated quickly, leading to her receiving abusive emails:

'Well I did, when I was in the first group, it was suggested, well it was just put out there, the psychologist was great, and she just said there's this online voice hearing group. So I was involved in that, but in the end, I got some rather abusive emails, which I reported to the police, and I was uncomfortable with it because the focus was on voice hearing being a terrible thing, and it was a bit removed from well-being I think' (Interview 9).

One participant also recounted how in one group, conflict arose outside of the meeting through a correspondence through the group email list which was connected to the face to face group. His comments further suggest the way in which peers might behave differently in face to face and online settings:

'We've had a recent situation ... apparently there was someone who came to these meetings and afterwards there was an email exchange and

apparently he told this guy he was not really depressed, it was fake and all that. I mean if somebody said that to me, I'm in a healthy frame of mind now, I'm not depressed, it would just wash over me, I'd just say whatever, I know you're not well, I'll make allowances for you, whatever, don't care. But I think he's not in the same healthy place as me so he took it very personally and you know... so these things do unfortunately occur. I wasn't at these sessions but apparently it even led to this guy threatening this other guy, it didn't sound very nice at all... apparently he's been very well-behaved in the meetings, it's just in the emails afterwards' (Interview 5).

Several participants talked about the different ways in which conflict could be negotiated in an online peer support setting, when compared to a face to face group setting. The face to face group setting seemed to allow more space for conflict to be managed. Participants described additional feelings of respect between members of a face to face peer support group that arose out of a commitment to spend time physically in the same space together and the ability to follow up with individual members after conflict had taken place:

'You don't have this feeling online, this is someone I could, I really almost have to respect, because we're going to spend this time together. I don't know, there are quite extreme situations that can happen online, like any two people emailing each other, it might go wrong, and it might end up with 'I never want to see you again' ... Whereas if somebody walks out of a self-help group, and they're in distress, then usually, someone will go running out after them to check they're okay. There's more cohesion, there's more concern, there's more at stake' (Interview 1).

'No, because it's not just about one person. There are other people there so, other people can hear that, so it's important not to ruin the environment for other people also. So, you're important, so is the other person. The tactfulness is very important to have, because you can't respond as you would one to one, more direct, you have to bite your tongue' (Interview 4).

This was very different to how participants had responded to conflict in an online setting, where they tended to just shut down interaction if misunderstandings emerged:

‘I think sometimes when I’m talking and someone is way off what I’m saying, I would just close it’ (Interview 4 – describing experience of online support via an app).

An emotional toll

A couple of participants also described the emotional toll that attending a face to face peer support group could have, with initial meetings potentially making them feel worse about their condition. However, over time, both participants suggested that in the longer-term, these encounters have helped them to process their experiences:

‘Sometimes I would come away from a group meeting feeling worse than when I went... because of the depth of the conversation, it was actually, without me knowing at the time, bringing up deep traumas in me, bringing up feelings’ (Interview 11).

‘There have been times when I’ve been completely wasted after a group... but I can look back and think that really helped’ (Interview 14)

Around a quarter of participants also talked specifically about the impact of a suicide on both individuals and group members. They expressed a sense of collective responsibility towards other group members. As such, these events created a sense of failure and had significant repercussions for the group:

‘Whether we dissuade people from suicide is a moot point because on occasion I think, we haven’t, and despite people being in contact with other services, everybody’s failed. And that’s a big scar on the group psyche. Twice in 25 years. Over that time, we also lost people to cancer, a heart attack and so on and many people from the group went to their funerals. I think when the group is in contact with someone very distressed

it's been positive, because it's respectful. It's just that in at least one case, it wasn't enough' (Interview 1).

'It was something that we really struggled to cope with, it was an awful time (Interview 2 – referring to the suicide of a group member).

'.. people that I was in groups with, they died, and that's a massive thing ... if you think about the rates of suicide, for example, what does that do to the group dynamics, or what does it do to your understanding of you know, your own level of responsibility towards each other. It's quite a complicated thing' (Interview 8).

5.6.2 Maintaining well-being whilst supporting others

As described earlier in this chapter, patterns of reciprocal giving varied considerably over the different forms of peer support. Face to face peer support groups were recognised as providing the most ways for individuals to give to others and a unique opportunity to take on a role as a group facilitator. Whilst such roles contributed to well-being by creating feelings of usefulness and a sense of purpose, they also were, on occasion, a source of personal stress. Some participants described how they sometimes felt the weight of personal responsibility to others in the group and how they wanted to step back from this responsibility. Taking on the facilitator role also meant that individuals were not able to call on the other members of the face to face peer support group for support in the same way. One participant identified two ways to manage the stress of the facilitator role, firstly, by calling on informal one to one peer relationships, and secondly the support of national mental health organisations. However, this participant also described how support from the latter had reduced over the last 30 years.

Earlier in the chapter, informal one to one peer relationships were described, generally, as the most balanced form of peer support. However, a couple of participants also identified that, at times, this equilibrium became unbalanced, and that the amount of support their peer needed was too much, and detrimental to their own well-being. This meant that at times they needed to step back from informal one to one relationships, in order to protect their own well-being.

Group facilitator fatigue

Around a third of participants also described the potential negative impact of facilitating a face to face peer support group. Several participants had facilitated groups for several years and said that they would like to step back but felt unable to do so, because of their sense of personal responsibility towards the group and that they felt they would be letting people down:

'I think it's because I feel that I'd be letting down a lot of people if I stopped it, number one, I don't want to stop being involved, I'd like to be less involved if I had the choice now. Because we're run by myself and I'd like to have another organiser with me so we could share the work. What I'd like is to have another co-organiser and then I'd like actually to step back, and let someone take over the group. I did that once, it didn't work... I feel I'd let people down' (Interview 2).

'Well, at the start, now maybe it's a bit tougher because when I started two years ago it was a bit easier, I was more eager and because I always find it, in my life, very easy to help others' (Interview 4).

Several mentioned the fact that taking on the role of facilitator meant that they felt they could not share their own experiences in the same way, or seek the same emotional support from the group:

'You can't fall apart in front of people who you're actually facilitating a group for, so to some extent, you've got to stand a little bit apart. And perhaps not share in the same way you perhaps would if you were just attending as a member, not a facilitator' (Interview 2).

'It certainly meant over the years that I've found it harder to ask for help I think because you know, there's that bit of me which would be I'm the person that runs the group, you know what I mean' (Interview 13).

One participant also suggested that by being a facilitator, he was able to avoid focusing on (and potentially processing) his own feelings:

'I found that it's easier ... to help other people. I knew I could help others. That would be easy, easier for me, so that kept a distraction away from me' (Interview 4).

Ultimately, the stress of running groups could cause a facilitator to become unwell. This could lead to the closure or disruption to groups. One participants described the toll that facilitating a group could have as follows:

'It is quite stressful to take charge of a group, so often, they fall badly ill' (Interview 16).

Running a group alongside a peer, or accessing informal one to one support from a peer, was identified as one way in which it was possible maintain well-being whilst facilitating groups. One participants described how she had relied on one to one informal peer support to help her emotionally whilst she was acting as a facilitator for a group:

'So because I was running the group, I think most of the peer support I got was really from the lady I met at the hospital, and we ran the group together' (Interview 2) .

This participant also described the changes that had taken place in the support available to facilitators of peer support groups, which had previously been co-ordinated by national bodies. She felt that National Support Organisations now provided far less support for facilitators than they had in the past:

'No, because [National Depression Support Organisation] doesn't exist anymore, there is nothing now. We used to have regular meetings where group facilitators could meet, and share but that doesn't happen anymore. There's virtually no support left for facilitators now. And I think eventually, probably the groups are going to suffer for that. And certainly, starting up new groups will not happen easily as it used to, which is a shame' (Interview 2).

Maintaining boundaries in one to one informal peer relationships

A couple of participants also talked about the problems that can exist with boundaries in an informal one to one peer support relationship. One spoke about the impact of being available all the time, another talked about how she had had to withdraw at times because of the strain of supporting a peer:

‘But there’s a protective element ... because you’re so accessible [on your phone] all the time ... When I want to look at shopping, buy a bikini, I don’t want to have messages saying, I’m really struggling or whatever’ (Interview 8).

‘Yeah, we’ve not good for each other if we’re both feeling ill, but over these last six months, luckily for both of us, he’s been ill and I’ve been well. So, I’ve been able to maintain our friendship via phone calls and visits. Yeah, he’s my best friend and when I was back home, he used to look after me when I was ill. So, you know, it was just my turn to be there for him.’ (Interview 17).

These comments illustrate the way that peers sometimes needed to limit the amount of peer support they gave to others on a one to one basis in order to protect their own well-being. This suggests that sometimes a delicate balance exists in the reciprocity offered and received by peers in a one to one peer support relationship, and that giving too much to a peer can undermine personal well-being.

5.6.3 Funding problems, group closures and disruption

Finally, several participants who attended or acted as facilitators for a face to face peer support group talked about struggles to gain recognition of the work of groups from external funding bodies. This meant that even small amounts of funding (one group received £400 annually) were hard to come by. Some groups had seen reductions in funding or had been involved in groups that had closed:

‘...the funding for our group is ridiculous, the health authority give us £400 every year, and (name of facilitator) has to beg for it. I think it’s disgusting,

because you know, the state aren't providing any support for people and we're providing a big service and they're not prepared to invest in it' (Interview 3).

'The main problem with keeping it running is the funding, it is a massive headache' (Interview 4).

One participant talked about the difficulty in demonstrating the true value of groups within the evaluative criteria developed by funders:

'When you have a charity sector, it's not necessarily in their interest to support grassroots groups. They may have targets or performance indicators ... which water down what's actually being recorded, so there isn't necessarily evidence of all the ins and outs of how peer support is helpful or how to develop it into a grassroots or in depth movement' (Interview 8).

Closures of groups were seen to be disruptive with one participant describing how individuals 'were lost' after the closure of one organisation that had offered peer support amongst other activities:

'There was a good [peer] service a few years ago ... people found that so helpful, and then they closed, last April. And that's it, 2018, yeah, and people like 'what am I supposed to do?' You know? They were lost' (Interview 4).

Whilst none of the participants in this study had found their well-being to be personally affected by group closures, the comments of participants illustrate how external changes to funding and support for grassroots voluntary and community sector organisations could influence the peer support that individuals are able to access for their own well-being. The closure of groups was not unique to face to face support as several participants also mentioned the way in which online platforms come and go. Some made specific reference to a gap that had been left following the closure of the online 'Friends in Need' platform several years ago:

'...that was set up by Depression Alliance, mostly with the idea of putting people in touch so that they could start face to face groups, but there was

also online support. Yes, that was interesting, I didn't really feel quite at home there, the system was in some ways a little bit over complicated, I'm kind of surprised that Mind hasn't kept it on, because I think it would be helpful, and having spent the money developing it, I'm surprised they couldn't just keep it. Minimal amount of moderation, you know. But yes, I was a little bit annoyed when each of these projects folded because I lost all the content that I'd put up on there' (Interview 1).

The possible repercussions of closures to peer support services on and offline and reductions in support to grassroots face to face groups is further explored in the following discussion chapter.

5.7 Chapter Summary

In this chapter I have presented the findings from 18 semi-structured interviews conducted with individuals with experience of mental or emotional distress and experience of using more than one form of peer support. Understanding the use of different forms of peer support from an individual perspective has enabled new understandings around how different forms of peer support are used in combination or sequence and the benefits to well-being resulting from this engagement. Whilst some forms of peer support became part of an ongoing routine and 'safety net' for participants, others were more likely to be used less consistently, and primarily, in times of distress. Participants combined different forms of peer support to tailor the support they needed. For some, this involved using one or several forms of peer support alongside professional support. For others, peer support was an alternative to engaging in professional support services.

Thematic analysis also revealed several themes around how we conceptualise and define peer support. Firstly, the complexity and evolving nature of what could be a considered a form of peer support and the blurred boundaries between the possible categorisations of 'face to face group', 'online' and 'one to one' peer support. Secondly, ideas of what constitutes 'shared experience', with participants describing experiences of mental or emotional distress as unifying but only within certain parameters, with some face to face groups drawing clear boundaries around what kind of experiences of mental or emotional distress could be shared in the

group setting. Finally, ideas of peer friendship and the terminological complexities around peer support highlighted the importance of exploring what terms were meaningful for participants, and which do not perhaps commonly appear in policy discourses.

Attending face to face peer support groups, using online peer support and informal one to one peer relationships are recognised to make both unique and distinct contributions to individual well-being. These contributions are considered to be potentially transformative in three areas; by enabling processes of reframing experiences, in turn leading to feelings of self-acceptance, by generating new sources of social support and by creating opportunities for reciprocity, which led to increases in self-esteem. Different forms of peer support also played an important and distinct role in supporting individuals to develop coping strategies and maintain their day to day well-being, namely as sources of practical information and by providing safe spaces.

Engaging with different forms of peer support also posed different challenges to well-being. Whilst experiences of conflict, misunderstanding and distress were present across peer support environments, these were negotiated differently on and offline. Specific challenges emerged around boundaries when it came to informal one to one peer support relationships and acting as a facilitator to a face to face peer support group. These demonstrate the challenges that can emerge for individuals when they are seeking to support peers alongside maintaining their own well-being.

The implications of these findings for our understanding of different forms of peer support are discussed in the next chapter.

Chapter Six

Discussion

6.1 Introduction

In the contextual chapter of this thesis, I discuss how the last fifty years have seen considerable changes in the peer support landscape in the UK. In addition to increasing complexity and fragmentation, facilitated by technological advances and social-political movements, there has also been an increasing emphasis on intentional and formal forms of peer support in both policy and research. This thesis seeks to rebalance the latter emphasis by focusing on community-based peer support, and most significantly, by considering the use of different forms of peer support together, rather than in isolation. The central research question informing this study is:

‘How do people who have experienced mental or emotional distress use different forms of community-based peer support to enhance their well-being?’

Within this, I have sought to explore:

- Motivations of individuals for accessing different forms of peer support
- Pathways between different forms of peer support
- Types of participation and patterns of use
- Barriers to accessing different forms of peer support
- Individual perceptions of how different forms of peer support enable participants to enhance their well-being

In this chapter, I reflect on my findings and explore what additional insights can be derived by taking a pluralistic approach to peer support. This is presented in five thematic areas. Firstly, I consider the implications of this study for how we define and conceptualise peer support. Secondly, I discuss how personal agency influences why and how individuals use different forms of peer support. Thirdly, I consider the contribution of this study to new understandings of how different forms of peer support are used by individuals to enhance their well-being and fourthly,

how engaging in different forms of peer support can potentially hinder individual recovery. Finally, I reflect on the overall implications for our understanding of the wider peer support landscape as well as for policy and practice.

6.2 How we define and conceptualise peer support

One of the challenges of completing a study on peer support is the myriad of terms used in the research literature, policy and practice. I became increasingly aware of this when undertaking my literature review and the number of search terms needed to cover the different fields and disciplines within which research on peer support has emerged. However, from my experience as a practitioner in community development, and the ubiquitous presence of the term 'peer support' in the charity sphere, I expected this term to be broadly familiar across individuals accessing different forms of community-based peer support. It was a surprise to me, and an important finding, that in fact many individuals were not familiar with this term; with some commenting on how it lacked meaning for them, or how they felt it to be associated with more formal forms of peer support. Specifically, when it came to groups, some individuals preferred the term self-help, or identified themselves primarily by the experience of mental distress which brought them together (such as a hearing voices group or depression support group).

Seebohm, Munn-Giddings and Brewer (2010) remind us that the terminology used around such support relationships is infused with meaning and significance and as such it is important to understand what terms individuals themselves find meaningful. Whilst the term 'peer support' might be used widely by large charities and in policy, it is not a term which is used as commonly at the grassroots. A recognition of this is perhaps at its most important when individuals are first looking for support with their experiences of mental or emotional distress. My findings demonstrate how many initially stumbled unintentionally across peer support when looking for support more generally. For others, whilst there was an intentional desire to engage with others with similar experiences, they might not use the language of 'peers'. My study has also illustrated how, in the most informal one to one peer support relationships, these are often simply referred to as 'friends', despite a recognition of the unique support that can be offered by friends with direct lived

experience of mental or emotional distress, when compared to friends without such lived experience.

These findings have implications for how we categorise and conceptualise different forms of peer support. Gillard (2019), in a reflection of peer support in mental health services, already questions whether we should call formal peer support workers operating in clinical settings something different. This study confirms these definitional challenges of peer support and questions whether it is possible to use single terminology across so many different kinds of support relationships between individuals with lived experience of mental or emotional distress. Whilst Bradstreet's (2006) overarching categories of peer support broadly encompass the different environments in which peer support takes place, more attention should be paid to the considerable variety of activities that sit within each of these categories and the features that define them. It is also important to note that moving away from terms such as 'self-help groups' in policy literature could lead to the loss of the legacy of a considerable body of work, a risk recognised by Borkman (2021).

This study also adds an important finding around the role that informal one to one peer support relationships play for individuals as they seek to enhance their well-being and develop a sense of personal recovery. The design of this study allowed for participants with experience of formal or informal peer support to come forward, as long as this was in community-based settings. Whilst very few participants had experienced more formal or 'intentional' forms of peer support, such as working with a peer support mentor or volunteer, many identified informal one to one peer relationships or friendships.

With the exception of the thesis study by Galloway (2016), which looks at the role of one to one informal peer support in clinical settings, such informal peer support relationships are often hidden; the way in which it becomes embedded in the day-to-day support networks and social lives of participants' means that it is not always recognised as a unique form of peer support. For some participants, it was only in the reflexive space of the interview that they were able to definitively recognise the friendships they had formed with others with direct experience of mental or emotional distress in this way. However, the findings of this study demonstrate that informal one to one peer support relationships were perceived to make numerous

important contributions to individuals' well-being. It is also important to note the time and circumstances which allowed such relationships to form. This required sufficient opportunities for those with lived experience of mental or emotional distress to socialise or meet with others over time until one to one relationships can build up organically, with some such relationships taking over a year to develop, either in another peer support environment or in some form of mental health services. As I will discuss later in this chapter, this highlights one important inter-dependency between different forms of peer support.

6.2.1 Key ingredients/ features of peer support

Numerous key features of peer support were discussed in the opening chapters to this thesis, namely the importance of shared experience as well as ideas of recovery, levels of ownership/ control and reciprocity. Recognised definitions of peer support, such as Mead (2003) and Solomon (2004) also highlighted the importance of both giving and receiving support as well as mutual respect and empathic understanding. These are all themes that have emerged in this study, however the findings have created new questions around what the 'essence' or most important ingredients of peer support might be, especially when different forms of peer support are used in sequence or combination, for different purposes. The complexity of the peer support landscape adds weight to suggestions from academics such as Borkman (2021) for the need to move away from simple definitions to more accommodating discussions around the characteristics of peer support.

In their 2012 study, Faulkner and Kalathil argue that a shared experience of mental or emotional distress may not be enough for someone to be considered a peer and that having a shared cultural background or specific life experiences (such as experiences of inpatient psychiatric care) might also be important. However, in this study, many individuals talked of the unifying nature of experiences of mental and emotional distress and how, especially in a face to face group setting, they felt this in itself was able to cut across different ages, genders, cultures and life experiences. In addition, several participants found it helpful to engage with others from different backgrounds because of the variety of perspectives this brought. For some, this offered a constructive challenge of their opinions and perspectives.

Some participants recognised that online peer support offered them a unique opportunity to choose and filter the 'peers' they engaged with. However, they did not generally talk of this as something they strongly desired or needed. Interestingly, informal one to one peer relationships were more likely to emerge when participants shared an interest, such as music, or a shared life experience such as being in psychiatric care.

What these findings demonstrate is that how individuals define and understand 'shared experience' is complex and it is important not to assume that an individual will always want or need to engage with someone with a very similar social or cultural background. What is important is that peer support is available in forms and environments that enables individuals to feel safe sharing their experiences and to connect with others. Such connection can, in part, be based on a sense of shared identity, and factors such as life stage, gender or interests were sometimes important in the formation of informal one to one relationships. However there are numerous instances where the behaviours of others and their willingness to offer acceptance and support was more important. These findings suggest the intersectionality that individuals employ when it comes to their identity in peer support environments, drawing on different elements of their identity and experience to build relationships. Intersectionality, a concept first introduced by Crenshaw in 1989 to explore the interaction of race and gender to understand experiences of discrimination, is already recognised to be important in the mental health literature (e.g. Torres et al 2018, Vu et al 2019). Whilst intersectionality is a concept that focuses primarily on experiences of discrimination, in a wider sense it draws our attention to the multiple identities to which we all hold.

As the focus of this study was on individual well-being, rather than the way in which different forms of peer support are organised and run, the levels of ownership and control offered by different forms of peer support was not an explicit focus. However, the way in which participants talked about their participation in all forms of community led peer support did suggest a sense of control and ownership, for example, this was expressed in terms of being able to create the parameters through which experiences of mental or emotional distress were discussed and conceptualised. This was most marked when compared to other forms of support, such as group therapy, where participants talked of frustrations about not being able

to engage with peers in the way they wished to (for example being able to meet outside of sessions) and of not being able to frame their experiences in a way which made sense to them.

Reciprocity and different ideas of recovery, also identified as key features of community-based peer support, have emerged as especially important themes and are covered extensively later in this chapter.

6.3 How personal agency influences why and how people use different forms of peer support

6.3.1 Deciding to use peer support

This study has strongly confirmed the importance of personal agency when it comes to decisions around why to use peer support. Zimmerman and Cleary (2006:45) define this as ‘one’s capability to originate and direct actions for given purposes’ and arguably, the decision to access peer support for the first time represents an individual desire to better understand and make sense of their experiences, and in doing so, find a path to recovery. The findings of this study demonstrate that decisions to use different forms of peer support are highly personal and often strongly depend on individual life circumstance. Lysaker and Leonhardt (2012:165) state that:

‘At its heart, the recovery movement asserts that people are not passive sites where biological and social forces meet, but agents who interpret their experiences and whose meaning making plays an essential role in outcome. To develop agency in the context of recovery from mental illness involves a range of discrete and more synthetic activities in which people are actively making meaning of their lives. To be an agent in a life with (or without) mental illness can mean deciding to do a particular thing (e.g., return to work) or to assert basic rights while facing injustice. To recapture agency can also, however, refer to regaining a larger experience of ownership and authorship of one’s thoughts, feelings and actions. Agency thus involves creating flexible and coherent accounts of the meaning of events which can be understood by others’.

Feelings of stigma and isolation drove most initial engagement with peer support, but individuals also took purposeful action at times of their lives when they felt themselves to be in need of additional support, such as leaving hospital, moving to a new country or after a change in life circumstances, such a divorce. They often chose to attend a face to face peer support group as part of their ongoing support and to use online support at specific times of distress or when they were looking for peers with a very specific life experience that they could not find in the group environment. Decisions were also taken to engage in alternative forms of peer support, such as attending a face to face group, when it was felt that no further benefit could be derived from engaging with online peer support.

It is of interest that whilst the increasing adoption of peer support practices into mental health services may be driven by efforts to introduce recovery focused services, various features such as the fixed programme of sessions and the unequal relationship between a peer support volunteer and the recipient of support could arguably detract from one of the most important elements of personal recovery journeys; the ability to take your own decision about the support you need and how you access it. Bejerholm and Roe (2018:420) argue that ideas of personal recovery are important because of 'the process by which a person attempts to develop new goals and meaning in life beyond the catastrophic event of having a mental illness'. This research has demonstrated the way in which individuals actively engage with and choose different forms of peer support in accordance with what their personal recovery journey requires. Therefore it is very important to avoid the assumption that one form of peer support will fulfil the needs of all individuals.

However, whilst individual agency is an important consideration in why individuals choose to access peer support, it must be remembered that this is exercised against an influential external landscape. Findings from this study demonstrated that initial engagement with peer support was both intentional and unintentional; some individuals were simply looking for alternative sources of support and happened upon peer support, others knew they wished to share their lived experience but were not aware of the different forms of peer support they might access. As discussed in the previous section the term 'peer support' is not always immediately familiar, and the use of different terms such as 'self-help group' 'support group' 'online support group' can be somewhat confusing. Online information is available;

NHS websites signpost to large national bodies, such as Mind, and online directories are available, however information is fragmented and may not feature smaller grassroots or user led organisations, who have fewer resources to promote themselves. Several interview participants also commented on how support from national mental health bodies had changed over time; with less resources and support being made available for the set-up of new groups. Even if decisions to access peer support are fuelled by personal agency, the fact that individuals can only access the peer support that is available to them means that there are external constraints to the choices they may wish to make. I reflect on what this means for how we fund and recognise different forms of peer support in the implications for policy and practice section of this chapter.

6.3.2 Personal agency and ongoing use of different forms of peer support

An appreciation of personal agency is also important when it comes to how individuals use different forms of peer support on an ongoing basis. Significantly, this study found that numerous individuals had engaged with peer support for many years; with some individuals choosing to maintain one to one informal peer support relationships and attend face to face peer support groups on a regular basis over decades. This was because individuals perceived different forms of peer support to be important as a safety net, to avoid falling back into crisis, and as a response to the cyclical nature of experiences of mental or emotional distress. Individuals also explained their long term engagement as a result of their progression into roles that enabled them to help others and to give back. Whilst individuals dipped into online support over long time periods, participation was not as consistent or frequent as for other forms of peer support.

In the initial review of the literature for this thesis, I discussed the work of Borkman (1999) and Behler et al (2017), who both recognise the value of longer term engagement with face to face peer support groups. In addition, although the timescales for the 2017 Evaluation of the Side by Side Programme did not allow for extensive exploration into the long-term use of peer support, there was a recognition that some individuals did engage on a longer term basis with face to face group support because of the ongoing social support it provided (Billsborough et al 2017). The findings of this study confirm the need to consider the long-term contribution of

peer support to individuals. Not recognising the reasons why engaging on a long term basis might be helpful underestimates the role that individuals play both in their own recovery and the recovery of others. Reducing ideas of recovery to symptom reduction over short time scales is reductive; it underplays both the challenge of living with experiences of mental or emotional distress over time and the complexity, and non-linear nature, of many personal recovery journeys.

Understanding patterns of participation across different forms of peer support also provides a new lens through which to consider ideas of active and passive engagement with peer support. Whilst several authors had previously recognised such different patterns in online peer support environments (van Uden-Kraan et al 2008, Carron-Arthur et al 2016), less was known about how this replicated across different peer support environments and whether such patterns of participation were static, or changed over time. Findings from this study suggest that participation in online support is generally more passive than in face to face environments (groups or one to one), and that changes in participation are most significant for those attending face to face peer groups, where members often recounted feeling unable to contribute initially but feeling more able to do so over time.

Numerous publications have found that more regular or active engagement with peer support result in greater gains for well-being (e.g. Behler et al 2017, Houston, Cooper and Ford 2002, Markowitz 2015). This can be potentially attributed to the increased access to forms of experiential knowledge, which in turn facilitates reframing processes (described by Borkman 1999 as 'liberating meaning perspectives') or to the increased opportunities for giving that come from engagement over time (Bracke, Christiaens, and Verhaeghe 2008). However, the findings from this study suggest that more passive engagement with peer support still makes some contribution to well-being, confirming findings from Carron-Arthur et al (2016). The mechanism for this being the ability for individuals with experience of mental or emotional distress to read and gain comfort from the experiences of others, for example a group newsletter or blog. Whilst it is often very difficult to capture and understand more passive engagement with peer support in research, it is important not to discount it, as this study has demonstrated it is another way in which individuals employ personal agency in order to maintain their well-being. Arguably, the dichotomy suggested by terms such as active and passive

engagement is unhelpful; an individual going online in a time of crisis is taking an active step and reaching out, even if they do not write about their own experiences online. It is important to accept that sometimes this is all people need, whilst also being aware of the reasons why individuals don't engage more actively with peer support.

Discussion of the barriers to engagement with different forms of peer support has underlined the importance of different peer support environments in providing 'safe spaces' for individuals to share their experiences, but also the complexity of what this involves. Boyce (2016:172-173), in her discussion of self-help groups for self-harm, identifies numerous practical features such as the 'approach to rules, confidentiality, regularity of group meetings, and consistency of group members, small group size and having a suitable meeting venue' which in combination with group values of non-judgement and commonality of experience, created an emotionally safe, non-judgemental space. In this study, participants identified numerous features across different forms of peer support that supported them to contribute and connect with others. Interestingly, online anonymity did not create a greater sense of ease or reduce inhibition (as proposed by King and Moreggi 2006, Reid 1994) but rather a fear of faceless mediums prevented numerous participants from engaging in peer support online. However, there was recognition of the importance of online peer support for individuals with social anxiety, for whom attending a face to face group was extremely stressful. For those who found face to face peer support groups helpful, confidentiality and acceptance were important factors in enabling participants in building the confidence to share their experiences, confirming the findings of Boyce (2016). An additional finding in this study was that some participants found the intimate space of an informal one to one peer relationship a safer or less risky space to share and process their experiences. These intricacies of what a safe space means to different participants are important and can be related to how trust is built in different peer support environments. Tschannen-Moran and Hoy (2000:566) define trust as:

'One party's willingness to be vulnerable to another party based on the confidence that the latter party is (a) benevolent, (b) reliable, (c) competent, (d) honest, and (e) open'.

Individuals accessing peer support are making judgements on whether they can be vulnerable in different spaces and multiple factors play a role in that decision. Trust often has to develop over time, demonstrated by the length of time an individual might attend face to face peer support group just to listen before sharing their own experiences, or the decision to read the comments of others online, rather than posting about your own experiences. It would seem from the findings of this study that building this sense of relational trust (Feldman 2016) can be more difficult online, where decisions on the competence and reliability of peers is taken without face to face interaction.

6.4 How individuals with experience of mental or emotional distress use different forms of peer support to enhance their well-being

The central research question for this study sought to understand how people with experience of mental or emotional distress used different forms of peer support to enhance their well-being. In my findings, there are three important areas where a pluralistic approach has highlighted the different ways in which different forms of peer support contribute to well-being. These are social support, reciprocity and self-esteem and re-framing experiences of mental or emotional distress.

6.4.1 Social support

This study started from the position of the classic theorists, Cassel and Cobb, who in their seminal 1976 publications, recognised the close relationship between social support and physical and mental well-being. Finding sources of social support is seen to be important for individuals with experience of mental distress as they seek to improve their well-being and to facilitate their personal recovery journey (Corrigan and Phelan 2004). As the initial review of the literature in this study demonstrated, research on the contribution of peer support as a source of social support to date is mixed. Whilst face to face peer support groups are commonly thought to be a source of social support (Behler et al 2017, Munn-Giddings and Borkman 2005), no consensus exists around whether online peer support is similarly able to provide strong support relationships and little is known about the contribution of more hidden informal one to one peer support relationships. The findings of this study strongly indicate that individuals often engage with peer support because of feelings

of stigma and isolation. Therefore, whether different forms of peer support can provide relief from such feelings of isolation is a very important consideration. This study has revealed important nuances around the different ways in which face to face groups, online support or informal one to one peer support relationships facilitate different forms of social connection and support. Confirming the findings of Munn-Giddings and Borkman (2005), and Boyce (2016), face to face peer support groups provide important physical spaces of belonging, where individuals are able to express themselves openly and find acceptance. However, they also provide a safe environment in which those who have previously felt unable to connect with others, because of their experiences of mental or emotional distress, can build social confidence and skills. Whilst groups themselves often become an important element of the social life of individuals with experience of mental or emotional distress, it is the informal one to one relationships which can result from attending face to face groups or accessing mental health services that often lay the basis for a wider social network and result in the deepest peer connections. Such relationships can take considerable time to develop and attending face to face peer support groups or mental health services on a regular basis (such as the social activities facilitated by recovery colleges) provides the opportunity for such relationships to develop gradually over time.

The difficulty in pinning down the contribution of peer support to social support is perhaps because of the multifaceted and complex nature of social relationships and different forms of social connection. Brown and Luckstead identify two sub dimensions of social integration, namely 'an interactional dimension and a social network dimension' (2010:22). They argue that forms of Mental Health Self Help (MHS) can inherently facilitate interaction with other community members and new social networks by providing a way to meet and connect with new people through different peer support settings. The findings of this study also confirm the position of Brown and Luckstead (2010:22) that the social support provided by peer support, whilst valuable, can be limited to 'a narrow band' of mental health consumers. Whilst for some participants, the safety of living in 'a mental health bubble' was reassuring, some participants explicitly expressed a desire to connect more widely beyond their peer support network. This raises important questions about the extent to which face to face peer support groups promote wider community integration. Authors such as Munn-Giddings and Borkman (2005) have identified that face to

face peer support groups can enable individuals to develop skills which they can then transfer to other environments. In this study, face to face groups were identified explicitly as a stepping stone and a space to develop new social skills but how this enables engagement with wider communities was not explicit.

For some, connecting in a face to face environment is challenging and online peer support provides an important route to connection for those experiencing social anxiety and for whom the group environment was stressful and unhelpful. Such connections were helpful in that even knowing others are experiencing similar challenges can offer respite to feelings of isolation and loneliness and, for a small number of participants, online support was identified as a form of social support. However engagement with peer support online did not demonstratively provide a direct pathway to other forms of peer support and interviews with a small number of participants suggested that online peer support offered limited opportunities to develop strong social support networks or relationships. An important area of future inquiry remains to understand under what circumstances strong relationships develop in online peer support environments or translate to off-line settings.

6.4.2 Reciprocity/ self-esteem

In my review of the existing literature on peer support, I drew attention to the importance given to reciprocal relationships as a key feature of peer support. Such relationships are viewed to be important because of the way they can enable individuals to develop a sense of competence and self-esteem by helping others (Reissman 1965, Skovholt 1974). The literature on peer support has recently started to look at how levels of reciprocity vary across different forms of peer support and the implications this potentially has for individual well-being (Billsborough et al 2017). The findings from this study add several further important insights to understandings of reciprocity in different peer support environments. Firstly, it confirms, as suggested in the evaluation of the Side by Side Peer Support Programme (Billsborough et al 2017), that considerable benefits are derived from giving in a face to face peer support group environment. Face to face groups seemed to be unique in the way they facilitate individuals to slowly build up how much they gave to others as they gained confidence in a peer support environment. Described by Munn-Giddings and Borkman as 'serial reciprocity' (2018), this is

seemingly a feature unique to face to face group environments. Also unique to the face to face group peer support environment was the possibility in taking on roles such as group facilitator, committee member or social secretary. These roles enable more giving to others and in doing so, contribute more to an individual sense of purpose and identity. However, individuals also recognised the very reciprocal nature of informal one to one peer support. This was an important source of self-esteem and well-being for participants, and was where the most natural balance or equilibrium was found in peer support relationships. For the participants of this study, online peer support was not perceived to be an important source of reciprocal relationships. Findings from the evaluation of the Side by Side Peer Support Programme did suggest that some individuals did see themselves as giving something back through their participation in online peer support, although this was not as significant as in a face to face group environment (Billsborough et al 2017). However, participants in this study primarily either described themselves as seeking comfort solely from reading the posts of others, rather than posting themselves, or seeing online forums as a way to post information for others, but not seeking reciprocal support.

An important consideration here is whether we should discount less reciprocal forms of peer support as they arguably do not offer the same opportunities for individuals to develop a sense of self-esteem and purpose. It was of considerable interest to me that participants in this study considered peer created newsletters as a form of peer support, even when they had no role in its creation. Such forms of peer support still created a sense of connection and belonging, albeit a weaker one than that experienced by regularly attending a face to face peer support group. As such, even without reciprocal engagement, such forms of peer support contribute something (more subtle) to individual well-being and their recovery journey.

Hagerty et al (1992:173) conceptualise two dimensions of a sense of belonging; firstly, 'valued involvement: the experience of feeling valued, needed, accepted' and secondly 'fit: the person's perception that his or her characteristics articulate with or complement the system or environment'. They argue that in addition to potential shared characteristics, an individual must desire meaningful involvement and have the energy to become involved for a sense of belonging to develop. The findings of this study suggest that such a sense of belonging may be strongest in a setting

such as attending and contributing to a face to face peer support group, where both dimensions of fit and value are fulfilled, and that reciprocity is an important element of this. However, there is the suggestion that receiving a peer newsletter can be a form of virtual community where individuals feel they 'fit' and can potentially contribute (as peers have done), even if they choose not to do so. Hagerty et al (1992:174-5) propose three consequences from a sense of belonging: '(1) psychological, social, spiritual, or physical involvement; (2) attribution of meaningfulness to that involvement; and (3) fortification or laying down of a fundamental foundation for emotional and behavioral responses'. It is notable that their conceptualisations allow for a number of different forms of involvement. Whilst this study has indicated the importance of a sense of belonging and how this varies across different forms of peer support, this is an area which would merit further investigation.

This study has also brought new insights when it comes to considering the balance of giving and receiving in peer support environments. Bracke, Christiaens, and Verhaeghe (2008) find an important link between this balance and the development of a sense of self-worth. This pluralistic approach builds on this by focusing on important nuances of reciprocity across different forms of peer support. It is of considerable interest that the most balance in giving and receiving was found in informal one to one peer support relationships where participants found a natural equilibrium developed. However, a few examples were given of where too much support was needed and this could lead to co-dependency or a breakdown in the relationship or the need to step away, in order to avoid detrimental effects to personal well-being. Acting as a facilitator to a face to face peer support group was also recognised as a source of stress; taking on such a position in which you are giving a lot to support other group members sometimes meant that individuals could not themselves disclose as much to the group, or seek support from the group. The implications of this are discussed later in this chapter in a consideration of the emotional toll of different forms of peer support. Participants demonstrated personal agency in responding to possible imbalances, for example, calling on informal one to one peer support relationships where they felt unable to share in a group because of their facilitator role.

6.4.3 Reframing experiences of mental or emotional distress

Academics such as Borkman (1999) and Rappaport (1994) have both pointed to the important role that peer support can play in building new narratives around experiences of mental distress, that differ to wider societal narratives, and which are less stigmatising 'meaning perspectives' than professional narratives. In a group face to face peer group environment, it is access to new forms of experiential knowledge that help to facilitate this process. Borkman (1999:15-16) explains how

'subjectively based knowledge that integrates the feelings, thought and ideas about the experience... a reflective process is necessary to convert 'raw experience', which is often a jumble of inchoate images, thoughts, impressions and feelings, into knowledge (which implies some form, coherence and meaning). The reflective process can be done by oneself, or with others, as when one talk's about one's experience. A key point about self-help groups is that the reflective process is done with others who have specialised knowledge about it and a personal stake in its interpretation'.

Munn-Giddings and Borkman (2005:142-143) further explain the mechanisms by which this takes place in a face to face peer setting, detailing the importance of storytelling as a way to communicate experiential knowledge, and how listening to the stories of peers in group setting enables individuals to learn 'what about their experience of living with the focal problem is unique (because of their total life context) and what is common to many of their peers'.

In this study, participants identified five different mechanisms that can contribute to processes of reframing or sense-making. It is of particular interest that some mechanisms were accessible through any form of peer support whilst others were unique to one specific form of peer support. The first of these, processing by listening to others in face to face peer support group, confirms the findings of Munn-Giddings and Borkman (2005). However, of importance, is that similar benefits were not explicitly found in informal one to one peer support relationships, or by reading about the experiences of others online. The main contribution of informal one to one peer relationships was to provide space for in depth explorations of experiences of mental or emotional distress. This was a process that complemented attending a

face to face group, where sometimes it was not possible to talk at length of your experiences because of the need to balance contributions between group members, but also one to one peer environments were also seen to some participants as safer spaces to make in-depth explorations. Face to face peer support groups were also spaces where participants were able to identify role models, which in turn contributed to their sense of hope, and were described as spaces of negotiation and dialogue which were constructive in challenging existing perceptions. All forms of peer support facilitated an element of re-framing or sense making by increasing awareness of the experience of others, however this was described by participants as less significant than the other mechanisms mentioned here.

The various communication styles facilitated by different forms of peer support played an important role in how individuals were able to re-frame their experiences. It was described how face to face peer support groups enabled participants to hear the perspectives of many others but allowed a fairly limited time to share your own experiences. Informal one to one relationships allowed the time and space for deep explorations of participant experiences, and additional time to tell your story in full. Online, there was a suggestion that the additional effort of typing your experiences may mean that individuals felt less able to share their experiences in detail, although this is an area which would certainly merit further investigation. Also of relevance was the way in which ideas were negotiated by peers in these different environments, with the suggestion that there was less dialogue and co-construction of knowledge compared to face to face settings. Where participants were able to engage in constructive challenge, this was recognised to be helpful to how they reframed or reinterpreted their experiences.

6.5 How engaging with peer support can challenge the recovery journey

6.5.1 Experiences of conflict and distress

Despite the contribution that different forms of peer support make to well-being, it is also important to acknowledge the pressures that engaging in peer support can potentially have, and whether these might play a role in hindering individual recovery journeys. Of particular interest to the academic community has been the potential for individuals to encounter adverse experiences online (Easton et al

2017), although it has been recognised that this is not an experience which is unique to online environments (Clarke and Smith 2003, Longden, Read and Dillon 2017). Whilst experiences of distress were not the primary focus of this study, and as such participants were not those who had chosen to disengage from peer support as a result of an adverse experience, thematic analysis identified several interesting findings and contributions to this discussion. Firstly, there was a common recognition across participants that conflicts do occur in all peer support environments and that these could result in distress for an individual. These were generally as a result of differing opinions, and sometimes a peer trying to help 'too much'. However, sometimes they were more substantial, with one example given of a situation when a peer denied another's experience of mental or emotional distress as genuine. A second experience of potential distress was identified as resulting from the topics of meetings themselves, both hearing of the distressing experience of others and revisiting difficult experiences from your own past. Some participants described how they might feel worse or drained from attending face to face peer support meetings for this reason. Thirdly, in face to face peer support groups, a sense of shared responsibility towards other group members could be a source of distress, if a member of the group committed suicide.

Longden, Read and Dillon (2017), when exploring the results of a survey of hearing voices groups, makes the important observation that being able to talk about distressing topics in the safe space provided by face to face peer support groups is an essential part of the recovery process and this study confirms these findings. Participants recognised that although it was difficult and draining to revisit such experiences, or sometimes to hear about the experiences of others, this was an important way in which they started to process and understand their experiences, which ultimately contributed to their well-being. Where participants engaged in online forums simply by reading about the experiences of others, they did not seem to experience the same emotional response, however they also did not contribute so significantly to an individual's ability to process and understand their own experiences. The peer support spaces that felt the safest enabled participants to take more risks in disclosing their own experiences, and in doing so finding the most benefit. Again, an important consideration here is how much individuals decided to give or share in different peer support settings and in doing so, exercised a sense of individual agency.

A final significant finding around conflict and distress was how it was negotiated in online and off line settings. Participants in face to face peer support groups described how a sense of responsibility to fellow group members or an unwritten group contract, allowed for experiences of conflict to be negotiated and overcome, whereas online someone was more likely simply to withdraw if upset by comments from others. There were less opportunities online for follow up, for example, if someone suddenly exited online in comparison to a face to face peer support group. Brief mention was also made in a small number of interviews to the way in which individuals would also behave differently online to a face to face environment, acting more aggressively in online communication. King and Moreggi (2006:233) argue that a disadvantage of online, text based groups is that:

‘Members negatively affected tend to drop out of the group. Only the “sturdy” group members, those not overly put off by the occasional flame war or by messages disruptive to the group process are left to answer any research question’.

This study has confirmed that whilst conflict can occur in any peer support environment, the way it is managed by the peers involved, and subsequently the consequences of conflict, can differ.

6.5.2 The potential emotional toll of different forms of peer support

A further important consideration and a consistent theme in the findings from this study, was the emotional toll that individuals could experience from supporting their peers, specifically as a facilitator of a face to face peer support group or from supporting a peer in an informal one to one relationship. Whilst feelings of responsibility did provide individuals with a sense of purpose which was helpful for their individual well-being, this emotional load could become too much, ultimately meaning that peers had to withdraw from one to one relationships to support themselves or step away from facilitator roles. This again highlights the important balance of giving and receiving that underpins peer support relationships and how giving to others is a delicate balance which can both contribute to and detract from individual well-being.

Some individuals described how they have found ways to protect themselves, through a pluralistic approach to peer support. One illustration of this being where long-term facilitators called on their informal one to one peer support relationships when they needed support. Others had found more organisational solutions, introducing committee type structures or sharing facilitation across several group members. However, it was also recognised that some sources of external support for group facilitators, such as opportunities for facilitators of different groups had diminished as a result funding cuts in the voluntary and community sector. Some facilitators also found themselves with the additional burden of worrying about funding for room hire or refreshments, to the extent they even considered paying this out of their own pocket. This situation is a consequence of the forms of peer support we value, fund and support in the UK and it is to a consideration of this the chapter now turns.

6.6 Implications for understanding the peer support landscape, policy and practice

The pluralistic approach to peer support employed in this study reveals the complex way in which individuals engage with different forms of community-based peer support and the important role that very informal forms of peer support can play in contributing to individual well-being. This can be missed when forms of peer support are considered in silo. Examining from a participant perspective also results in rich data and a more in-depth understanding around the intentionality and agency with which individuals engage with peer support. The importance of individual agency when it comes to decisions around how to engage with different forms of peer support is not always addressed or acknowledged in the wider literature, despite ‘enabling people to be active participants in their recovery’ being one of the elements that was identified to be important by The Scottish Research Network Narrative Research Project (Brown and Kandirikirira 2007).

In the opening contextual chapter to this study, I argued that in the last fifty years, a number of important societal and political trends had influenced the peer support landscape in the UK. This landscape is the backdrop against which individuals can exercise individual agency and as such there are two important considerations for policy makers and practitioners; firstly, how we situate different forms of peer

support alongside traditional mental health services as part of the wider welfare landscape in the UK, and secondly how we fund and support different forms of peer support.

The findings from this study clearly demonstrated that individuals chose to use peer support both as a complement and an alternative to professional services. For some, with a lack of trust in medical professionals and who do not wish to engage with mainstream mental health services, peer support is a way to access support without having to submit to medical interpretations of experiences of mental or emotional distress. However, other participants commented how having access to different forms of support, and different frameworks of knowledge to understand and process their experiences, was helpful. In their 2002 paper, Barker and Pistrang argue that the divisions we often place between psychological helping and informal helping or social support are 'unnecessary and unproductive'. Rather than being considered in distinct bodies of literature, they argue, the analysis of both should be integrated. To some extent, I agree with this. It was clearly evident from the interviews I undertook that participants could find an informal one to one peer relationship as useful as a session with a therapist. However, whilst both should be valued equally, and positioned together as part of different packages of support individuals might choose to engage with, it should not be necessary for individuals to engage with mental health services in order to access forms of peer support. The referral conditions mentioned earlier in this study, whereby it was necessary to be engaging with primary care services to be referred to certain peer support services could be a barrier to some when seeking peer support as an alternative to mental health services. We should also be mindful of how some forms of peer support act as gateways to others; many informal one to one peer support relationships originated from attending face to face peer support groups. As such, if groups are not able to survive, this could potentially take away access to more than one form of peer support.

Whilst the growing recognition of peer support is welcome, it is important to consider what value judgements are attached to the forms of peer support we promote, fund and research. In Chapter Two, I made several international comparisons with countries such as Norway and Germany to illustrate the different ways in which peer support has been positioned alongside professional health services. These

comparisons also demonstrate how national policy plays an active role in shaping peer support landscapes. Numerous participants in this study talked of funding problems, specifically for peer support in the form of user led, grassroots groups. Such groups had very minimal running costs, needing only to fund room hire and refreshments, but often struggled even to secure a few hundred pounds a year. This was an ongoing source of stress for facilitators, one of whom had even considered funding the group out of his own pocket in order to avoid letting other group members down.

The findings of this study strongly demonstrate the importance that community-based peer support, in all forms, had to the well-being of participants. Whilst peer support in general is valued, and national policy documents talk, again in general terms, of the contribution of the voluntary and community sector (for example in No Health without Mental Health, 2011), arguably the role it plays in our overall health and well-being landscape is confused. The findings of this study suggest that greater clarity should be given to community-based peer support as a complement and alternative to mental health services. This requires both forms of support being considered as equally valuable.

Funding in the voluntary and community sector is often fragmented and in many cases, only available for new project based work, rather than covering the ongoing costs of ongoing groups and services. Research from the National Survivor User Network suggests that many face to face groups have closed in recent years (NSUN 2019). We should also be mindful of how some forms of peer support act as gateways to others; many informal one to one peer support relationships originated from attending face to face peer support groups. As such, if groups are not able to survive, this could potentially also take away access to more than one form of peer support.

There is no easy solution as to how to create the conditions for all forms of community-based peer support to thrive. Examples from nations such as Norway have demonstrated how a national funding approach can have unwelcome repercussions for community-based peer support, with new restrictions or a new positioning as a depository for 'heart sink patients' (Hedlund, Landstad and Tritter 2019). Seebohm et al (2013) also discuss the appropriateness of

commissioning for grassroots face to face peer support groups, recognising that the burden of reporting output figures such as attendees is both an administrative strain and undermines the value that such groups offer. However, in a follow up to their 2013 'Jigsaw' report, the national charity Mind has sent out a survey asking groups what support they need and this potentially will create a useful evidence base for future policy.

6.7 Chapter Summary

A pluralistic approach to peer support identifies new complexities in how we define and conceptualise peer support, highlighting both the importance of terminology and the essential features we subscribe to peer support. It also provides a more detailed and nuanced understanding of how different forms of peer support can contribute to the well-being of individuals with experience of mental or emotional distress, specifically in the areas of reciprocity, social support and reframing. It also strongly confirms the importance of individual agency when it comes to decisions around why and how to use peer support and how these represent the important and active role of individuals in their own personal recovery journeys. Finally, the findings of this study raise new questions for how we value, research and fund different forms of peer support, and in doing so shape the peer support landscape in the UK.

Chapter Seven

Conclusion

7.1 Introduction

I set out on my research journey to look at how individuals with experience of mental or emotional distress use different forms of peer support to enhance their well-being. This study has introduced a new pluralistic approach and perspective through which to consider individual peer support journeys and, in doing so has illustrated how individuals chose to intentionally engage with different forms of peer support over years, and sometimes decades. I have situated the study within an interpretivist research paradigm and drawn on data from 18 semi-structured interviews with individuals with experience of more than one form of peer support to explore the research question.

In this chapter I draw the key conclusions from my study. Firstly, I present the unique contribution of my study. I then explore the limitations of this thesis, primarily challenges faced by data collection around peer support in community-based settings. In the third section, I identify ideas for future research. Finally, I reflect on my own personal research journey and how undertaking this thesis has enabled me to develop myself as a researcher.

7.2 Original research contributions

This study both consolidates and adds to the existing body of research, and our understanding, of how different forms of peer support contribute to the well-being of individuals with experiences of mental or emotional distress. By applying a pluralistic approach and interviewing individuals with experience of more than one form of peer support, it has been possible to explore the complex way in which different forms of peer support are used from a real life, person-centred perspective. Researchers often draw artificial lines between forms of peer support as a means to consider their unique contribution. However, doing so, does not allow for the interplay between different forms of peer support, how they might be used in combination, or the decisions leading individuals from one form to another.

This in-depth, exploratory study offers new insights into this complexity and the importance of how different forms of peer support are used together, as well as in isolation. In taking this approach to the research question; 'How do people who have experienced mental or emotional distress use different forms of peer support to enhance their well-being?', the findings of this study offer a unique perspective on the way in which personal agency plays an important role in how and why individuals use different forms of peer support.

Individuals experiencing mental or emotional distress often first engage with peer support because of feelings of stigma or isolation and a sense that they are unable to access support from professionals or from existing social networks of family and friends. A choice to engage with peer support can also be triggered by a life change, such as divorce or moving country.

At the start of this thesis, I identified a clear gap in knowledge around how different forms of peer support were used in combination or sequence. This study makes a unique contribution by illustrating the way in which individuals experiment with, and try different forms of peer support to find that which best enables them to improve their well-being. The majority of participants in this study (14 out of the total of 18) had some experience of using different forms of peer support in combination. Many participants attended a peer support group and had ongoing informal one to one peer support relationships outside of the group setting. Participants also described using an online peer support when they were unable to find a shared emotional response in a face to face group setting, or as a way to enhance the face to face group experience (keeping in touch between meetings for example). Some individuals also chose to engage with peers online, as an additional form of support, in times of crisis or difficulty. A few individuals used online peer support for a short period, of around six months, before engaging with a face to face peer support group and finding this to better meet their needs.

Patterns of engagement across different forms of peer support are not uniform and individuals chose both to use forms of peer support on a regular or routine basis, and to dip into additional forms of peer support on an adhoc basis. The length of engagement also varies considerably, from six months to over twenty years. Individuals are most likely to draw on a face to face peer support groups or informal

one to one peer support relationships on a long-term, continuous basis to maintain well-being. Face to face peer support groups also appear to offer individuals particular opportunities to progress through different forms of participation. It is perhaps for this reason that face to face peer support is most commonly that which becomes part of the daily routine for individuals. The accessibility of online support is beneficial particularly to individuals in times of distress but does not lend itself in the same way to extended periods of engagement.

The varied way in which individuals use different forms of peer support illustrates the importance of individual agency when it comes to decisions around how and when to engage with different forms of peer support. However, it is important to remember that individuals can only access that which is made available to them. This research has demonstrated how individual decisions are exercised against an influential external landscape and how access to different forms of peer support is shaped by contemporary policy, research and funding.

Individuals recognise the unique and nuanced way in which different forms of peer support have contributed to their well-being. These differences are most prominent in the diverse ways that online, face to face peer support groups or informal one to one peer support relationships enable individuals to reframe their experiences of mental or emotional distress, source new forms of social support and participate in reciprocal giving with others. Different forms of peer support also offer practical support in varying degrees and can be safe spaces, where individuals can discuss and process their experiences of mental or emotional distress.

Those using different forms of peer support also recognise the way in which they can also pose a challenge to their well-being. Experiences of conflict or misunderstandings are encountered across all forms of peer support but managed differently on and offline, and in one to one and group peer relationships. Maintaining individual well-being and boundaries whilst supporting others can also be a difficulty, primarily for individuals acting as facilitators of face to face peer support groups or those supporting a peer informally, on a one to one basis.

In this section, the original research contribution is presented in two areas; conceptual/ theoretical contributions and the methodological contribution of this study.

7.2.1 Conceptual/ theoretical contributions

Firstly, this study has re-confirmed the importance of the language around peer support, and the meaning this may or may not have for individuals seeking support from others with similar lived experience of mental or emotional distress. Numerous terms are used in both policy and practice, including self-help, support group and friendship. The term 'peer support' is not recognised or universal to all, and it is important to remember this as how we describe forms of peer support may influence who is able to access it. Additionally, moving away from terms such as 'self-help groups' in policy literature could potentially result in the loss of a considerable amount of work of understanding around peer relationships (Borkman 2021).

Secondly, and related to the terminological complexities mentioned above, are new implications for how we categorise and conceptualise different forms of peer support. In this study, I question whether it is possible to use single terminology across so many different kinds of support relationships between individuals with lived experience of mental or emotional distress and argue that more attention should be paid to the range of peer support activities that sit within the broad categories proposed by Bradstreet in 2006 and the features that define them. The findings of this study have created new ways to frame the 'essence' of peer support and consider what the most important ingredients of peer support might be, especially when different forms of peer support are used in sequence or combination, for different purposes. One example of this, illustrated clearly by the findings of this study, is the complexity around ideas of 'shared experience' and the extent to which experiences of mental and emotional distress can be unifying (or not) across ages, genders, cultures and life experiences. Additionally, ideas of reciprocal giving within peer support have been highlighted as more complex than as a dichotomy between reciprocal and non-reciprocal support. Whilst the opportunity to give to others is an important distinguisher between professional and peer support relationships, and giving to others has clear benefits to well-being, other, less reciprocal forms of peer support are also important to individuals, and

make a contribution to their well-being. As such, they should also be recognised as part of the landscape of peer support.

Also of conceptual significance is the way in which this study has drawn particular attention to the valuable role of informal one to one peer support relationships, which can be hidden, and consequently can fall beneath the radar of researchers and policy makers. The findings of this study clearly demonstrate that informal one to one peer relationships make an important and unique contribution to the well-being of individuals with experiences of mental or emotional distress. Whilst 'informal peer support' is recognised in Bradstreet's 2006 categorisation of peer support, very few research studies have previously explored this area in depth.

This study has both strongly confirmed and demonstrated the agency with which individuals engage with different forms of peer support with individuals calling on different forms of peer support both in sequence and combination to underpin their personal recovery. For many participants, peer support is about choice. For some, this is a choice to engage with peer support alongside professional mental health services, for others, as an alternative. Not recognising the different choices being made by individuals as they engage in various forms of peer support takes away the essential role that individuals play in their own personal recovery. However, whilst individual agency is an important consideration in why individuals choose to access peer support, it must be remembered that this is exercised against an influential external landscape, and this has implications for both policy and practice.

Beyond initial engagement, an appreciation of personal agency and recovery is also important when it comes to how individuals use different forms of peer support on an ongoing basis. This enables a new understanding of the frequency and length of time for which individuals use peer support, and whether this is considered as a positive aspect of individual recovery journeys (with individuals finding effective coping strategies that enable them to maintain well-being or respond to times of crisis) rather than a lack of progression towards recovery. Not recognising why individuals find it helpful to engage with peer support on a long-term basis, underestimates the role that individuals play both in their own recovery and the recovery of others, as well as the often non-linear nature of recovery journeys.

Coming into this study, there was a recognition from some academics, that the mechanisms of peer support in different environments are not always well-understood (Watson 2019c). This study has provided a far more nuanced understanding of the ways in which different forms of peer support can contribute to individual well-being, specifically in the areas of 1) reframing experiences, leading to self-acceptance, 2) the development of social support networks and 3) reciprocal giving, which can underpin improvements in self-esteem. These processes do not operate in a uniform manner across different forms of peer support and it is important to recognise the limits that different forms of peer support might have for individuals, as well as the opportunities to enhance well-being.

Across different forms of peer support, five processes were identified to contribute to reframing or sense-making, which ultimately enabled individuals to develop self-acceptance. Some forms of peer support offered a unique way to process experiences, such as the in-depth explorations offered by one to one informal peer support or the opportunity to listen to a variety of experiences in face to face support groups. Underpinning these differences was a recognition of the diverse ways in which ideas were negotiated across peer spaces and how being able to engage in constructive dialogue was important to how individuals reframed or reinterpreted their experiences.

Distinct patterns of reciprocal giving were also observed across different forms of peer support. Individuals recognised that they gave more in some peer support environments than others, with face to face peer support groups offering the most support to give more over time, and informal one to one relationships facilitating the most balanced reciprocal giving relationships. The findings of this study have raised an important new question around whether we should discount less reciprocal forms of peer support as they arguably do not offer the same opportunities for individuals to develop a sense of self-esteem. I have argued for the importance of understanding the benefits that more 'passive' or non-reciprocal participation can have for individuals, as even receiving a peer newsletter or reading posts on a forum can create a sense of belonging and connection which, in turn, also contributes to individual well-being.

Finally, this study has demonstrated several important nuances around the diverse ways in which face to face groups, online support or informal one to one peer support relationships facilitate different forms of social connection and support. Peer support environments can offer new spaces of belonging and the opportunity to develop social skills, a means by which it is possible to build a wider social network and possibilities for connecting whilst experiencing social anxiety. Previous studies that seek to understand how individual forms of peer support facilitate new forms of social support report mixed findings. This study demonstrates the complexity of the processes underpinning forms of social support and how individuals may seek out or value different forms of social support, depending on their personal circumstances.

These unique contributions raise new questions for how we value, research and fund different forms of peer support. If peer support is positioned solely as a means to reduce hospital admissions or reduce symptoms, or if the outcomes from engaging with peer support are only considered within one-year timescales, much of the value of peer support to individuals with experience of mental or emotional distress could be lost. Such conceptualisations and definitions have repercussions for the funding and support available, and ultimately, could lead to some forms of community-based peer support disappearing altogether. Therefore, policy must embrace complexity and plurality and be aware of the weight and value it subscribes to different forms of peer support and why.

7.2.2 The methodological contribution of this study: pluralism and well-being approaches

As noted in Chapter Three of this study, two frameworks have been employed to understand the outcomes that come from using different forms of peer support. Bio-medical or treatment evaluation studies seek to measure how engaging with peer support activities reduce the symptoms of mental illness and possible subsequent reductions in use of mental health services. In stating the rationale for this study, I argued that well-being approaches, based on constructivist approaches with qualitative methods, offered a way to understand potential benefits of peer support in a way which has meaning to the individual. In practical terms, the research design of this study employed purposive sampling to allow individuals to come forward with

the forms of peer support that were meaningful to them. The use of semi-structured interviews enabled participants to talk about their experiences in their own terms, and to communicate their own ideas of peer support, well-being and recovery. The findings of the study demonstrate the value of this approach and how, whilst attending a face to face group on a regular basis might not completely alleviate symptoms of depression, as measured on a validated scale, it can still make meaningful contributions to individual well-being and personal recovery. Lysaker and Leonhardt (2012:165) argue that

‘By understanding the intersubjective requirements of the experience of agency, we can see that legitimacy of subjective accounts of wellbeing rests on whether or not they can be understood and accepted by others. This is not to say that there are objectively right or wrong answers. For instance, meaningful accounts of threats to wellbeing can accept or reject the medical model and still be understood by others.’

Accordingly, we must be aware of the value systems that infuse our choices of how best to demonstrate the outcomes of peer support and how they approach questions of personal agency and conceptualise ideas of recovery. The social movements of the 1970s, which saw peer support emerge onto the mainstream agenda are recognised to be a reaction to bio-medical understandings of mental health;

‘The recovery movement is not only a reaction to paternalistic practices but also a response to certain scientific paradigms which emphasized outcome as the result of the interaction of larger social and biological forces, neglecting the role played by individual persons as they make their own sense of what is happening in their lives’ (Lysaker and Leonhardt 2012:165).

The adoption of treatment evaluation studies which seek to understand how peer support might contribute to symptom reduction in short-term time scales alone removes decisions around why people use different forms of peer support, and in doing so, can lose an important area of understanding. They also represent a specific idea of recovery as a linear process of symptom reduction. The findings of this study demonstrate the way in which, for some, experiences of mental or

emotional distress are cyclical, and engagement with peer support is part of the ongoing management of these experiences and a safety net for specific times of distress. Therefore, using peer support on a long-term basis does not necessarily mean you are 'stuck' in your recovery journey. As such, the findings of this study strongly reaffirm ideas of personal recovery as an ongoing and non-linear process. This conceptualisation of recovery is described by Bejerholm and Roe (2018:422):

'Personal recovery is an ongoing process and a human journey of finding a way to live a meaningful life and develop valued social roles in the community even when symptoms are present. The process is nonlinear and deeply personal. It is a process during which a person tries to take stock of their life and identity. It often involves the person identifying what he or she would like their life to look like, and begin to sketch a map of how to get there while seeking the needed support and acquiring the needed skills. The right to one's personal story is as crucial as the right to reject the names and labels which they were expected to passively adapt to. Personal recovery does not refer to clinical recovery and symptom reduction, but rather to constructing a personally meaningful life of choice'.

For some of the participants of this study, this was an ongoing journey over decades. We must therefore adopt and recognise research methodologies that capture the complexities and length of personal recovery journeys. The pluralistic approach of this study has done this by looking beyond traditional research boundaries which have tended to consider forms of peer support in isolation. By exploring the experiences of individuals who have chosen to use more than form of peer support, and not pre-determining timescales around the period of use, it has been possible to identify new patterns of participation and nuances around how individuals use different forms of peer support to enhance their well-being. In doing so, the study has created a new lens to capture the complexity of ongoing personal recovery journeys and how such journeys are supported by different forms of peer support over time.

7.3 Limitations of this study and challenges posed by community-based research

During my study, I faced numerous constraints whilst collecting my data. I recognise that this may have introduced elements of bias into the findings in two areas; firstly, my findings are slightly less representative of users of online peer support, and secondly, that my findings are slightly skewed towards older individuals, and not as representative of individuals aged 18 – 35. However, in addition to recognising the potential impact of this on my findings, it is also important to reflect on what caused these constraints and wider implications for research on peer support in community-based settings.

Accessing individuals engaging in online peer support was challenging for a number of reasons. For this study, I took the decision that I should only seek to recruit users of online forums by way of contacting moderators and asking permission to post information about my study. Whilst it would have been possible to simply join Facebook groups as a user myself and to post information, myself and my supervisors felt that this was an intrusive step into an environment which was designed for support, not research study recruitment. However, moderators from several large national online forums declined to post information about my study on their sites again because they felt this would encroach on a safe space and participants might feel pressured to participate against their will. One national charity has allocated a particular thread to research projects, so that users could simply visit this particular discussion if they found it to be of interest, but advised me that they charged £800 per post from researchers, and this was outside of my means as a PhD student. My experiences illustrate the complexity of engaging with vulnerable individuals online without compromising their well-being in any way. However, it also serves to demonstrate the incredibly important role of large gatekeeper organisations and how their willingness to accommodate external researchers can play a considerable role in shaping what research is possible in the community sector.

This was not a challenge which was limited to online peer support. When I contacted local, regional or national mental health charities, to ask if it might be possible to attend a face to face peer support group to explain my research, I was

often told this would not be possible because individuals engaging with these groups were already being interviewed or being asked to respond to surveys to provide information to funding bodies. It would seem that increased monitoring and reporting in the voluntary and community sector can create a reluctance for charities to engage with independent academics because they wish to protect their users from being 'over questioned' or feeling they have to take part in something which makes them feel uncomfortable. However, by not even offering the opportunity for their users to engage in external research studies, they are potentially disempowering those they actually seek to empower. Participants who did take part in this study often did so to raise the profile of peer support, to share their considerable experience, but also as part of their recovery journeys, and as part of the way they made sense of their experiences. Whilst no one should ever be pressured into taking part in a research study, individuals should be given the opportunity to make their own decision. The evaluation reports commissioned and produced by national mental health charities are extremely important and make a valuable contribution to the research landscape, however there is also a need for independent research and evaluation in the field of community-based peer support beyond that which is commissioned by charities themselves.

Whilst I found grassroots groups to be far more responsive, even here, group facilitators and participants described how in recent years, the growing interest in mental health and peer support had led to community-based groups becoming inundated with requests to participate in research studies. Several spoke of 'research fatigue' and the time and energy they had already devoted to supporting other research studies. Compensation was also mentioned, with one facilitator talking about how one study had offered £50 per participant for undertaking an MRI scan. It is important to understand the pressures that constant requests for research participants might put on grassroots groups and this again begs the question of how to balance the need for research and better understanding in this field against the needs of individuals with experience of mental and emotional distress.

7.4 Areas for future research

There are numerous areas of research which would benefit from further consideration.

Firstly, this has been a small scale in-depth exploratory study which has looked in depth at the experiences of a relatively small number of individuals of different forms of peer support. It is not yet possible to say how such experiences are replicated more broadly. As such, it would be of considerable interest to conduct a large scale survey to apply this pluralistic framework and to understand the potential influence of regional or national policies.

Secondly, whilst this study has identified several unique insights around online peer support, several questions remain. Future research could focus on a number of areas, such as the circumstances under which individuals choose to use online support frequently or on an ongoing basis, the factors contributing to longer-term social relationships online and whether such relationships convert to face to face relationships.

Thirdly, this study has identified some of the complexities around what could cause distress in different peer support settings, and how experiences of conflict and distress are managed on and off-line. However, as this is such a complex area, with the potential to have a profound impact on users of peer support, it would be helpful to devote more attention to experiences of conflict and distress in different peer support environments, to understand when these are constructive and destructive and how these experiences are managed in different peer support environments by groups and individuals.

Finally, research to understand how the COVID-19 pandemic has shaped the peer support landscape in the UK; how individuals have called on different forms of peer support in this time of crisis, or changed their use of peer support as a result of societal restrictions is a significant area which is still to be fully understood. One area of interest might be the differences between groups set up during the pandemic, and those that chose to move their activities online.

7.5 My reflexive journey

There can be no doubt that doctoral study is both a highly rewarding and highly challenging undertaking. I had no idea when I commenced my PhD of the mental stamina it would require, or that I would be attempting to complete my research against the backdrop of a global pandemic. However, in addition to the intellectual and practical skills I have gained from my research, I have also gained a better understanding of myself and the values I bring to my research.

One of the most influential training sessions I attended at Anglia Ruskin University looked at critical writing. The facilitator opened the session by asking us what the word thesis actually means, before advising us that one translation could be 'I believe'. In another session, a senior lecturer reflected back on his time as a PhD student and his own struggles to find 'his voice'. At the time, early on in my PhD journey, I did not really appreciate the significance of these observations. However, I can now see that this has been the most difficult and significant step for me. After years of presenting and discussing the academic arguments of others, I was required to put forward my own argument, a firm proposal of what I believed, based on my data. This has required me to make myself vulnerable to others, with my arguments open to discussion and critique. I understand now what it is to seek new knowledge and understanding and see reflections of this in many areas of life. Individuals engaging in peer support, in whatever form, also seek new knowledge about themselves and their experiences, and in doing so also make themselves vulnerable. However, as this research has demonstrated, they have often found such efforts rewarding and essential for their own personal journeys. Ultimately, despite the many twists and turns of doctoral research, I am grateful for the opportunity it has afforded me to find my own voice and to trust the quality of my own research endeavours.

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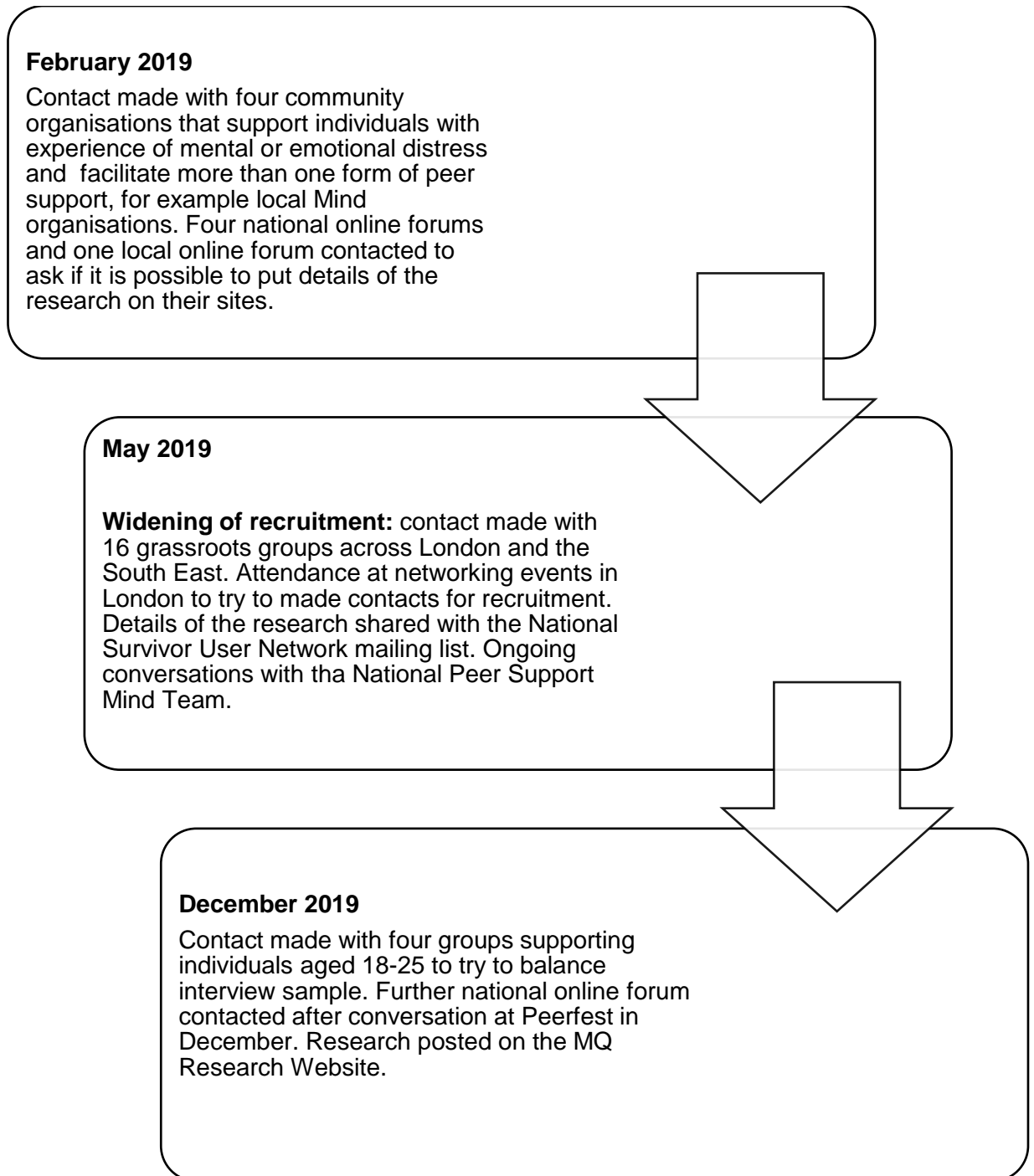
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Appendix One: Participant Recruitment



Appendix Two: Interview Guide

Introduction:

- To myself
- To the research and what it is looking at, how the findings will be used.

Research question: how do people who have experienced mental or emotional distress use different forms of peer support to improve/ enhance their well-being?

- Check consent for recording interview.
- Ensure all consent forms completed and understood
- Remind participants they do not have to answer any questions they feel uncomfortable with and that they can take a break at any time

At beginning of interview clarify what the different forms of peer support are and draw a timeline with participant about the types they have accessed at different times, give examples of what different types of peer support might be.

SECTION ONE: Motivations/Benefits/Challenges

Motivation for accessing Peer Support

- Can you tell me why and how did you first become interested in peer support?
- Who do you consider to be a 'peer' or someone who has had a similar experience to yourself?
- What did you hope to gain from accessing peer support?
- How would you describe your first experience of peer support?

SECTION TWO: Pathways and Patterns of peer support

Pathways

- What other types of peer support have you been using? And for how long?
- Why have you tried more than one type of peer support?
- After accessing (first type of peer support), why did you decide to access (second type of peer support)? How did you find out about each type of peer support?
- Do you use different forms of peer support for different reasons?

Frequency and pattern

- When do you access different forms of peer support (frequency/ times e.g. evenings/ daytime)?
- Is there a particular reason you access different types of peer support at different times?

SECTION THREE: Benefits and challenges of different types of peer support

- How would you describe the benefits of peer support? What did you find helpful about the peer support you accessed?
- Is there anything you have found difficult about accessing peer support? Have you experienced any barriers or problems in accessing peer support?

Advantages and disadvantages

- Have you found any particular advantages or disadvantages to different forms of peer support?

Similarities and differences

- What do you feel is similar about different types of peer support?
- What do you feel is different about different types of peer support?

Comparison to other types of support (family, friends, clinical services)

- How does the support you receive from peer support compare to other types of support, for example, support from family or friends or from mental health services?

SECTION FOUR

Impact and outcomes of peer support (clarify type of peer support)

- In what ways, if at all, has peer support had an impact on your life?

Prompts:

- How you feel about yourself?
- helped you gain any new skills (e.g. in managing condition or broader skills such as presenting/chairing/ confidence)
- Influenced your relationships to others?

SECTION FIVE

Future involvement

- Will you continue to use peer support in the future? What are your reasons for doing so? If no, why not?
- Is there anything you would like to add to our discussion?

For the purposes of the research it would be helpful, if you feel willing to give me:

- How you define your gender?
- Your age?
- How you define your ethnicity?
- Where you live (city)?

Many thanks for all your time – much appreciated

Appendix Three – Ethical Approval Paperwork



**Anglia Ruskin
University**

24th October 2018

Cambridge & Chelmsford

Chelmsford Campus
Bishop Hall Lane
Tel: 01245-493131
Int: +44 (0)1245-493131

Eleanor Townsend

Dear Eleanor

Principal Investigator	Eleanor Townsend
SREP Number	FHEMS-DREP-18-010
Project Title	A Pluralistic approach to peer support

I am pleased to inform you that your ethics application has been approved by the School Research Ethics Panel (SREP) under the terms of Anglia Ruskin University's Research Ethics Policy (Dated 8 September 2016, Version 1.7). Approval by SREP is subject to ratification by the FREP.

Ethical approval is given for 3 years from 24th October 2018. If your research will extend beyond this period, it is your responsibility to apply for an extension before your approval expires.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Research Ethics Policy and the Code of Practice for Applying for Ethical Approval at Anglia Ruskin University available at www.anglia.ac.uk/researchethics including the following.

- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these amendments until you have received approval from SREP for them.
- The procedure for reporting accidents, adverse events and incidents.
- The General Data Protection Requirement and Data Protection Act (2018).
- Any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. This includes other Higher Education Institutions if you intend to carry out any research involving their students, staff or premises. Please ensure that you send the SREP copies of this documentation if required, prior to starting your research.
- Any laws of the country where you are carrying the research and obtaining any other approvals or permissions that are required.
- Any professional codes of conduct relating to research or requirements from your funding body (please note that for externally funded research, where the funding has been obtained via

Anglia Ruskin University, a Project Risk Assessment must have been carried out prior to starting the research).

- Completing a Risk Assessment (Health and Safety) if required and updating this annually or if any aspects of your study change which affect this.
- Notifying the SREP Secretary when your study has ended.

Please also note that your research may be subject to monitoring.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely,



Dr. Niamh O'Brien (Co- Chair)

For the FHEMS School Research Ethics Panel (SREP)

T: 0845 196 4197

E: Niamh.obrien@anglia.ac.uk

Copy to: Carol Munn-Giddings



Anglia Ruskin
University

16th May 2019

Cambridge & Chelmsford

Chelmsford Campus
Bishop Hall Lane

Eleanor Townsend

Dear Eleanor

AMENDMENT – 16TH MAY 2019

Principal Investigator	Eleanor Townsend
SREP Number	FHEMS-DREP-18-010 - AMENDMENT
Project Title	A Pluralistic approach to peer support

I am pleased to inform you that the **AMENDMENTS** you requested to your ethics application have been approved by the School Research Ethics Panel (SREP) under the terms of Anglia Ruskin University's Research Ethics Policy (Dated 8 September 2016, Version 1.7).

Ethical approval is given for 3 years from 24th October 2018. If your research will extend beyond this period, it is your responsibility to apply for an extension before your approval expires.

Please also note that your research may be subject to monitoring.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely,

Dr. Niamh O'Brien (Co- Chair)
For the FHEMS School Research Ethics Panel (SREP)
Education & Social Care

T: 0845 196 4197

E: Niamh.obrien@anglia.ac.uk

Copy to: Carol Munn-Giddings



26th March 2020

Eleanor Townsend

Dear Eleanor

AMENDMENTS – 26th MARCH 2020

Principal Investigator	Eleanor Townsend
SREP Number	FHEMS-DREP-18-010 – AMENDMENT 26.3.20
Project Title	A Pluralistic approach to peer support

I am pleased to inform you that the **AMENDMENTS** you requested to your ethics application has been approved by the School Research Ethics Panel (SREP) under the terms of Anglia Ruskin University's Research Ethics Policy (dated 24 July 2019, Version 1.11). This application has also been approved by FREP.

Ethical approval is given for 3 years from date 24th October 2018. If your research will extend beyond this period, it is your responsibility to apply for an extension before your approval expires.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Research Ethics Policy and the Code of Practice for Applying for Ethical Approval at Anglia Ruskin University available at www.aru.ac.uk/researchethics including the following:

- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these amendments until you have received approval from the SREP for them.
- The procedure for reporting accidents, adverse events and incidents.

- The General Data Protection Requirement (GDPR) if your research will take place in the European Economic Area (EEA)¹ or involve sending or bringing any personal data² into it. If your research will take place in the UK or involve sending or bringing any personal data into it, you must also comply with the Data Protection Act (2018). Other countries in the EEA may have further data protection legislation you must comply with. If your research will take place outside the EEA, you must comply with any data protection legislation relating to that country or countries.
- Any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. This includes other Higher Education Institutions if you intend to carry out any research involving their students, staff or premises. Please ensure that you send the SREP copies of this documentation if required, prior to starting your research.
- Any laws of the country where you are carrying the research and obtaining any other approvals or permissions that are required.
- Any professional codes of conduct relating to research or requirements from your funding body (please note that for externally funded research, where the funding has been obtained via Anglia Ruskin University, a Project Risk Assessment must have been carried out prior to starting the research).
- Completing a Risk Assessment (Health and Safety) if required and updating this annually or if any aspects of your study change which affect this.
- Notifying the SREP Secretary when your study has ended.

Please also note that your research may be subject to monitoring.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely,



Dr. Niamh O'Brien (Co- Chair)
For the FHEMS School Research Ethics Panel (SREP)
Education & Social Care

T: 0845 196 4197

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Copy to: Carol Munn-Giddings
 Melanie Boyce

¹ The EEA includes EU member states and also Iceland, Liechtenstein and Norway.

² Personal data means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

Appendix Four: Participant Information Sheet and Consent Form

Participant Information Sheet – Interviews

Understanding how people use different forms of peer support to improve well-being.

My name is Eleanor Townsend and I am a PhD student at Anglia Ruskin University. I am inviting you to take part in a research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. There is more information about me and my professional background at the end of this information sheet.

What is the purpose of the study?

We know from previous research that people who have experienced mental or emotional distress can benefit from using different forms of peer support, such as attending a peer support group, using an online forum or through a one to one relationship with someone with a similar experience. However in the UK we do not yet know how people use different forms of peer support together to improve their well-being or about their experience accessing different types of peer support. The purpose of this study is to develop a better understanding of how different types of peer support can be helpful to improve individual well-being.

Why have I been invited?

You have been invited to take part as someone who has used more than one type of peer support (attending a face to face group, online or one to one support) and can talk about your experience. Your involvement will be very valuable in helping us to develop a better understanding of how people use different forms of peer support to improve their well-being.

Do I have to take part?

No. It is up to you to decide whether you would like to take part. If you do agree to take part you will be given a copy of this information sheet to keep. You will also be asked to sign a consent form. If you do decide to take part you are free to withdraw from the study at any time during the interview, and you can withdraw your data until data analysis has taken place (after which your data will have been anonymously aggregated with other participants' data). If you do wish to withdraw your data after the interview all you need to do is let me know either by phone, email or using the withdrawal slip on the consent form within one month of your interview. Non – participation will not affect the support you receive from your organisation.

What will I have to do?

If you decide to take part you will be asked to take part in an interview at a time and community space convenient for you. The interview will last about one hour and I will ask you about:

- Your experiences of different types of peer support
- Your motivations in accessing different types of peer support
- How you have used different forms of peer support to improve your well-being
- Any barriers you experienced when trying to access peer support.

If there are any questions you would prefer not to answer, just tell me and I will move on to the next question. So that I can listen to your views without having to take notes I would like to audio record the discussion and will ask your consent to this before we start the interview.

Will my part in the study be confidential?

Anything that you say during this interview will be strictly confidential. Any information that you provide will be reported in a way that makes sure you cannot be identified as an individual. If any of our discussions are recorded these will be erased once it has been transcribed. You will receive a copy of our discussion to agree accuracy and the transcript will be kept in a password protected computer file, which only I will have access to. I will be transcribing each interview myself and quotes in the final report will be anonymised.

What are the possible benefits of taking part?

There will be the opportunity to be made aware of how other people have benefitted from using different types of peer support. You will also be contributing to a better understanding of how peer support can help improve well-being.

What will happen to the results of this study?

The results of the study will be written up and form part of my PhD thesis. I will also produce a summary of the key findings for all participants taking part which will be available at the end of the research, in 2020. I will also send a summary of the findings to interested organisations.

Who is organising and funding the study?

The study is being organised by myself with my supervisors as part of my PhD research. There is no funding or involvement from any external organisation.

Who has reviewed the study?

This study has been reviewed and approved by the Anglia Ruskin University Faculty of Health, Education, Medicine and Social Care Department Research Ethics Panel.

What happens next?

If you would like to take part, please fill in and provide your contact details in the consent form attached and return it in the stamped addressed envelope provided. Alternatively you can email me on X to express interest in taking part in the study. I will then contact you to arrange a convenient time and date to undertake the interview. On the day of the interview I will reconfirm your consent and we will both have a copy of the signed consent form. If you do not want to take part you do not have to do anything else.

Contact for further information:

Thank you for taking the time to read this information. If you have any questions or would like any further information about this project please contact me:

Eleanor Townsend

Anglia Ruskin University, Faculty of Health, Education, Medicine and Social Care, Michael Salmon Building, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ

Email:

If you have any concerns you wish to direct to my supervisor, please contact Professor Carol Munn Giddings by email at x or by phone on

You can also write to the following address: Anglia Ruskin University, Faculty of Health, Education, Medicine and Social Care, Michael Salmon Building, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ

Contact details for complaints

If, after speaking to myself and my supervisor, you wish to address any complaints directly to Anglia Ruskin University, you can contact the Office of the Secretary and Clerk using the details below:

Email address: complaints@anglia.ac.uk

Postal address: Office of the Secretary and Clerk, Anglia Ruskin University, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

Some information about me...

I have worked in the public and voluntary and community sector for the past ten years. I first worked with communities as a Community Development Officer for Wiltshire Council. Then I worked for a social enterprise called Spice which use a time currency called 'Time Credits' as a way to recognise the time that people gave to others in their communities. I have also supported community organisations across London as a Development Manager for the charity Locality. In January 2018 I was accepted as a full-time PhD student at Anglia Ruskin University.

My interest in peer support has developed as a result of my work with health and social care organisations and communities. I have seen many people benefit from accessing face to face peer support and would like to better understand the benefits and challenges of different types of peer support.

My intentions are therefore to increase the understanding of how individuals can benefit from accessing peer support by working collaboratively and respectfully with individuals already accessing different peer support services.

Participant Consent Form - Interviews

NAME OF PARTICIPANT:

Title of the project: Understanding how people use different forms of peer support to improve well-being.

Researcher contact details:

Eleanor Townsend, Anglia Ruskin University, Faculty of Health, Education, Medicine and Social Care, Michael Salmon Building, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ,

Supervisor contact details:

Professor Carol Munn-Giddings, Anglia Ruskin University, Faculty of Health, Education, Medicine and Social Care, Michael Salmon Building, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

I WISH TO TAKE PART IN THIS STUDY:

Please initial in the box beside each statement below if you agree:

1. I agree to take part in the above research.	
2. I have read the Participant Information Sheet and I understand what my role will be in this research.	
3. I understand that I am free to withdraw from the research at any time before and during the interview, without prejudice, and without needing to give a reason.	
4. After the interview I understand that I can withdraw up to the point of data analysis, which will be one month after my interview.	
5. I have been informed that any information I provide will be confidential	
6. I understand that I am free to ask any questions at any time before, during and after the study.	
7. I agree to the interview being digitally voice-recorded for the purposes of transcription and data analysis.	
8. I agree that quotes from my interview can be used in the final study. I understand that these will be anonymised.	

Data Protection: I agree to the University processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me.

Name of researcher: ELEANOR TOWNSEND

Signed..... Date.....

Name of participant (please print name).....

Signed..... Date.....

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP.

YOUR CONTACT DETAILS

Telephone number:

Email:

Withdrawing from the research

If you do decide to take part you are free to withdraw from the study at any time during the interview, and you can withdraw your data until data analysis has taken place (after which your data will have been anonymously aggregated with other participants' data).

If you do wish to withdraw your data after the interview all you need to do is let me know either by phone, email or using the withdrawal slip below within one month of your interview.

Please return to x or post to Eleanor Townsend, Anglia Ruskin University, Faculty of Health, Education, Medicine and Social Care, Michael Salmon Building, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ.

Title of Project: Understanding how people use different forms of peer support to improve well-being.

I WISH TO WITHDRAW FROM THIS STUDY

Print name: _____

Signed: _____ Date: _____